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Autism Spectrum Disorder Diagnosis from the African American Parents' Perspective

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Dedication

This dissertation is dedicated to my grandmother, Francenia Barr Brown. She was my biggest cheerleader and lived vicariously through my educational pursuits. She passed away on September 20, 2016 and her memory lives on through me.

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I want to thank all of the participants for this study because agreeing to share personal details about your family life is difficult but the participants all gave so much of themselves. Each family that participated are the sole reason that this study was able to happen and I am eternally grateful. I also want to thank the ABA therapists and therapy centers that shared my research flyer through email, Facebook, and posted it in the waiting room of their establishments. Thank you for helping me connect with the participants. I also want to give a special thank you to my dissertation committee for giving their time and expertise to help me throughout this journey. Thank you Dr. Audrey M. Sorrells, Dr. Terry Falcomata, Dr. North Cooc and Dr. Allison Skerrett.

Abstract

Autism Spectrum Disorder Diagnosis from the African American Parents' Perspective

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Abstract: The purpose of this study was to attempt to understand the ASD diagnosis of an African American child by sharing the voices of parents that have navigated the diagnosis process. The following research questions framed the study: how do African American parents describe their experiences related to obtaining a diagnosis for their child with an ASD and I n what ways do these experiences help to explain factors that affect ASD diagnosis for African American children? Twelve African American parents participated in this instrumental case study that utilized interviews, a parent needs assessment and a review of archival data.

The themes that connected the experiences of those in the sample were the conviction that there was something not right, the drive to learn more about ASD, the desire to put the child first, and an understanding of how difficult ASD is for the African American community. The findings highlighted the impact of access to healthcare, quality evaluations, and the impact of the parent. Through analyzing the experiences of African

American parents with a child with ASD the data provides previously unrecorded access into the journey from the vantage point of parents.

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CHAPTER 1: INTRODUCTION

Autism spectrum disorder (ASD) refers to "a group of pervasive neurodevelopmental disorders that involve moderately to severely disrupted functioning regarding social skills and socialization, expressive and receptive communication, and repetitive or stereotyped behaviors and interests" (Pennington et al., 2014, p.1). The Individuals with Disabilities Education Act (IDEA) of 1997 defines autism as "a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, which adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences". The 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) identifies ASD through two major domains, impairment of social communication and social interaction in multiple contexts, and "restricted, repetitive patterns of behavior, interests, or activities" (American Psychiatric Association, 2013, p. 119). The concise nature of these recent definitions of autism illustrate the types of measures that have been utilized over the past decades by both educators and clinicians to better identify and characterize ASD.

The first documented account of autism as a separate disorder came in 1943, when Leo Kanner, a child psychiatrist, published "Autistic Disturbances in Affective Contact" in which Kanner described eleven children who had a disorder he called 'infantile autism (Kanner, 1943). Kanner characterized the symptoms of infantile autism

as an inability to maintain emotional contact combined with a strict preference for isolation, stereotypical, repetitive behaviors, and complications with communication and language (Kanner, 1943). At that time, it was believed that children developed autism because they were deprived of interpersonal, need-satisfying relationships from their mothers (Bettelheim, 1967), or that autism was a brain disorder (Rutter, 1968), or that it was a psychogenic disorder (Despert, 1951).

Confusion in the research community about the cause of autism continued until the Lockyer and Rutter's (1969) longitudinal study on autism revealed that language deficits and intellectual difficulties of the participants persisted over time if no intervention was present. The first systematic research studies on autism found that language and speech problems were not caused by severe affective withdrawal or a lack of motivation, but were instead due to a limited understanding of the meaning of spoken words (Frith, 1970; Hermelin & O'Connor, 1970).

These advances in the understanding of ASD led to a more systematic method of diagnosing autism. However, in the absence of a medical test to diagnose ASD, doctors analyze the child's behavior and development to make a diagnosis. By the age of two, a child could receive a reliable diagnosis by a clinician while some children can have ASD detected at 18 months or younger (Lord et al., 2006). Christensen et al. (2016) found that the average age of diagnosis for ASD is 46 months.

The number of individuals diagnosed with ASD has increased in the last 25 years, partially due to increases in societal and parent awareness (Fountain et al., 2011). Recent estimates predict that one in 68 children will be diagnosed with an ASD which is

approximately 1.2 million Americans under the age of 21 (Centers for Disease Control and Prevention, 2014). These most recent numbers show a 30% increase in the number of American children with an ASD reported since 2012 which was reported as 1 in 88 children. According to the 37th Annual Report to Congress on the Implementation of IDEA (2015), in 2008, a total of 5 percent of students ages 6 through 21 served under IDEA (2004) had an ASD diagnosis but in 2013, this number rose to 8.2 percent. Autism did not become a separate disability category in IDEA until 1990 under P.L. 101-476; however, students with ASD were previously covered by the law under other disability categories (IDEA, 1990).

ASD AND RACE

Initially, ASD was conceived as a disability that primarily impacted middle and upper-class White children (Bettleheim, 1967; Kanner, 1949). With this increase in prevalence and visibility of ASD, the age of initial diagnosis has decreased for individuals from families of a high-socioeconomic status (SES) and White families (Hertz-Picciotto & Delwiche, 2009). However, despite increased awareness leading to positive outcomes for some children, individuals from culturally and linguistically diverse (CLD) backgrounds have typically been under-diagnosed for ASD (Durkin et al., 2010; Fountain et al., 2011).

African Americans are one of the CLD groups that experience disparities in ASD prevalence. The U.S. Census Bureau defines African American or Black as a person that has origins in the Black racial groups of Africa; including individuals that identify

as Ghanaian, Jamaican, Black, or Negro (U.S. Census Bureau, Population Estimates Program (PEP), 2010). White is defined as a person with origins in any of the original inhabitants of Europe, North Africa or the Middle East, including people that identify as French, Egyptian, Irish or Caucasian (U.S. Census Bureau, Population Estimates Program (PEP), 2010). The overall prevalence of ASD in 2014 was estimated at 14.7 per 1,000 children; however, this rate for White children was higher, at 15.8 per 1,000 than the prevalence rates among African Americans at 12.3 per 1,000 (Centers for Disease Control and Prevention, 2014).

It is problematic that the rates of ASD in White children are higher than in African American children because there is a lack of research to explain this disparity due to a myriad of factors. This discrepancy is partly due to misdiagnosis because of symptoms such as delayed speech, difficulty connecting with others, and behavioral deficits, which may lead to a misdiagnosis of speech/language impairment or Attention Deficit/ Hyperactivity Disorder (ADHD). Even with the presence of misdiagnoses for children with an ASD, there are differences in the rates of misdiagnosis for African American Children when compared to their White peers. African American children are 2.6 times more likely to be misdiagnosed than White children, including 5.1 times more likely to receive a misdiagnosis of adjustment disorder and 2.4 times more likely to receive a conduct disorder misdiagnosis (Mandell et al., 2007).

Another factor contributing to diagnosis disparities is that the age of ASD diagnosis for White children is younger than for African American children. Mandell,

Listerud, Levy, and Pinto-Martin (2002) conducted a study of Medicaid eligible children in Philadelphia and found that the average age at first ASD diagnosis for African American children was 7.9 for White children it was 6.3 years old. The difference in age is directly related to the number of visits the children had until receiving the first ASD diagnosis. Mandell et al. (2002) found that the average number of visits before diagnosis for White children was 4.1 visits and African American children went to an average of 13 visits.

The evaluator often impacts the longer time frame for diagnosis; Emerson et al. (2016) found that 18.7% of White children were diagnosed by a primary care physician (PCP) and a PCP diagnosed 36.8% of African American children. Their PCP than a private evaluator diagnoses more African American children; however, when children are diagnosed by a specialty physician such as a mental health care provider, the disparities still exist. For instance, Mandell et al. (2002) found that 72% of the White children received an ASD diagnosis upon the first mental health visit; however, only 57% of the African American children received an ASD diagnosis on the first visit. Mandell et al. (2007) found that 34.7% of African American children were diagnosed with ASD on the first visit compared to 60.2% of White children. The number of PCPs, a child, has before receiving the ASD diagnosis also impacted the timeliness of the diagnosis. Children that had four or more PCPs before diagnosis received the ASD diagnosis on average six months later than their peers (Mandell et al., 2005).

Even if African American children receive regularly scheduled medical care and have access to specialty medical professionals, obtaining an ASD diagnosis can still be time-consuming and difficult. Obstacles include the costs of services, limited access to experienced service providers, and the cultural influence of how parents interpret symptoms and communicate with service providers (Mandell & Novak, 2005; Flanders et al., 2007; Ruble et al., 2005). Other disparities include the obstacles encountered with referral delays, physician uncertainty, and the complication of diverse symptoms (Goin-Kochel et al., 2006).

IMPORTANCE OF EARLY DIAGNOSIS

With adequate information regarding disparities, service providers, researchers and educators can better support African American parents in the arduous process of obtaining an ASD diagnosis and hopefully avoid delayed diagnosis and misdiagnosis. Delays often highlight a broader issue because parents report gaps in the timeline from noticing symptoms and delays and receiving a diagnosis (Sansosti et al., 2012; Shattuck et al., 2009). It is imperative to acquire an accurate early diagnosis because, with early detection, children can begin ASD-focused interventions. These ASD-specific interventions include applied behavior analysis, cognitive behavior therapy, parent training, social skills instruction and speech-language therapy. Kaiser, Hancock, and Neitfield (2000) found that toddlers diagnosed with ASD show improvements in early interactions if they are receiving high-dosage, intensive autism-specific interventions beginning at 18 months of age.

Early intervention is essential for children with ASD because it can lessen the impact of intellectual, behavioral, and functional impairments (Fountain et al., 2011). Children with access to high-quality, research-based, early behavioral intervention can have significantly better outcomes than children receiving interventions later. Children in early intervention develop improved developmental functioning, less maladaptive behaviors, have a reduction in symptom severity, and show improvements in language and socio-emotional skills (Eldevik et al., 2009; Rogers & Vismara, 2008). Early intervention can decrease developmental delays (Dawson et al. 2010) and atypical behavior (Boyd et al., 2011; Eikeseth et al., 2007) and increase critical skills including joint engagement (Lawton & Kasari, 2012), communication (Kaiser et al., 2000; Landa, 2007; Minjarez et al., 2011), symbolic play (Kasari et al., 2006), and imitation (Landa et al., 2011).

The benefits connecting early intervention to early identification are apparent; however, the early identification of children with ASD is commonly associated with higher socioeconomic status (SES). This association arises because parents typically possess higher levels of education and wealth, allowing the family to access specific resources that increase the likelihood their child will receive an early and accurate ASD diagnosis (Longtin & Principe, 2016). Parents that do not have access to resources may be less knowledgeable about their child's disability, potentially impacting the likelihood of their child receiving a timely and accurate identification and treatment of ASD. However, IDEA specifies that beginning at age three, children with disabilities can access special education services through the public education system. These free and

appropriate educational and related services for young children with disabilities can support children with ASD and their families, but without accurate early diagnosis, children will not have access to the services.

With differences in diagnosis rates, timelines and the presence of disparities in awareness, knowledge, and receipt of services, African American parents face added challenges to securing an early diagnosis for their child. The studies discussed previously show that obtaining a diagnosis is complicated for many parents. In addition, the delay of diagnosis postpones any interventions which ultimately, impacts the child's access to ASD specific interventions. However, there is a gap in the research regarding how African American parents can obtain an ASD diagnosis. The literature utilizes large data sets to analyze aspects of ASD diagnosis and to compare these findings amongst racial groups. The limited qualitative studies that include African American parents with a child with ASD have focused on parent satisfaction and resiliency. These studies provide meaningful contributions to the field however they also raise questions regarding why there are differences in how ASD is reported for African American students. As a result, it is unclear how diagnosis disparities impact the difference in the prevalence, severity, and age of diagnosis for ASD. This lack of clarity and the presence of unanswered questions from the findings in the literature led to the creation of this study to analyze ASD diagnosis in a different way in hopes of achieving a better understanding of these disparities.

PURPOSE AND SIGNIFICANCE OF THE STUDY

The purpose of this study was to attempt to understand the ASD diagnosis of an African American child by sharing the voices of parents that have navigated the diagnosis process. There are disparities in ASD diagnosis for African American children that are impacted by both race and SES; however, there is a lack of research to explain the complex intersectionality of these factors. The majority of research on diagnosis disparities is quantitative and incorporates sizeable national data sets; however, these studies do not explain why these disparities exist. Without knowing why prevalence rates, the age of diagnosis, and severity of the ASD diagnosis are different for African Americans, it is difficult to analyze diagnosis disparities accurately. Key contributors to understanding this issue are African American parents that have a child diagnosed with ASD because their experiences can provide insight that previous research lacks.

RESEARCH QUESTIONS

This study was guided by the following research questions:

- How do African American parents describe their experiences related to obtaining a diagnosis for their child with an ASD?
- In what ways do these experiences help to explain factors that affect ASD diagnosis for African American children?

Chapter 2: Review of the Literature

Despite, an increase in awareness and improvements in diagnostic practices of individuals with an Autism Spectrum Disorder (ASD), diagnosis-related disparities are present among African American with ASD. These disparities are present in the prevalence of ASD, the age of diagnosis, the severity of the disorder and factors that influence diagnosis disparities.

LIKELIHOOD OF ASD DIAGNOSIS

Travers, Tincani, and Krezmien (2011) analyzed data from the IDEA Data Accountability Center for 29 states and reported the odds ratios (ORs), the odds of being diagnosed with ASD between two groups, African Americans and Whites. In 2000, the OR of an African American child being identified with ASD was 0.97 ($p=.002$) and in 2007 it was 0.69 ($p<.001$). Travers et al. (2011) found that in 2007 no more than 0.5% of African American students were identified with autism in any of the twenty-nine states which are past the lower band of error (0.85%) in the CDC's 2006 estimate. This finding highlights that in these 29 states, African American children were diagnosed with an ASD less often than the CDC predicted a year earlier; however, seven states had prevalence rates for White students that were higher than the CDC estimate by 0.93%.

Travers, Krezmien, Mulcahy, and Tincani (2014) also reported over-identification, under-identification and proportionate identification for ASD based on race for each of the fifty states. In 2007, no states over-identified African American students with ASD but in 2000, eight states over-identified African American students with ASD (Travers et al., 2014). African American students were proportionately

identified with ASD in 11 states in 2000, but seven years later 10 of those states began under-identifying African American students (Travers et al., 2014). In 2000, seven states under-identified African American students, but in 2007 this number grew to 32 states (Travers et al., 2014). The oscillation between under and over-identification of African American children with ASD raises concerns regarding the lack of evidence to justify these changes.

Two cross-sectional studies utilized information collected by the Autism and Developmental Disabilities Monitoring (ADDM) network and health care providers reviewed the children's records. Christensen et al. (2016) collected data from eleven ADDM state sites in 2010 and 2012 and found that the prevalence of ASD was 14.6 per 1,000 children aged eight years for both years. Prevalence of ASD based on race varied and was significantly higher for Non-Hispanic White children (15.5 per 1000) than Non-Hispanic African American children (13.2 per 1000, PR: 1.2, 95% CI: 1.1-1.3; $p<0.001$) (Christensen et al., 2016).

Mandell et al. (2009) also utilized data collected by ADDM in 2002 from fourteen sites in Wisconsin, West Virginia, Utah, South Carolina, Pennsylvania, North Carolina, New Jersey, Missouri, Maryland, Georgia, Colorado, Arkansas, Arizona, and Alabama. Mandell et al. (2009) did not find statistical significance by ethnicity for children having an ASD classification noted in their records. However, African American children were most likely in the sample to have an IQ lower than 70 documented. This finding is significant because of the children with IQs lower than 70, African American, Hispanic and Asian children were less likely than their White peers to have an ASD diagnosis

documented. It is unclear what children with an IQ lower than 70 were diagnosed with, but the inference is that regardless of IQ, White children were more likely to receive an ASD diagnosis than their CLD peers.

Nicholas, Charles, Carpenter, King, Jenner and Spratt (2008) focused on ADDM data from only South Carolina and found that the overall prevalence of ASD was 6.2 per 1000 children (95% CI, 5.6-7.0), or 1 in 162 children. The population in the study area of Nicholas et al. (2008) was 49% White, 46% African American, and 5% Other (Multiracial, American Indian, Asian, Native Hawaiian and Hispanic). Their findings showed that 50% of the children with ASD were White, 42% were African American and 6% undetermined.

Using a sample collected by Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP), Jarquin, Wiggins, Schieve, and Naarden-Braun (2011) found that the odds for having an ASD diagnosis were 39% greater for Non-Hispanic African American children than their Non-Hispanic White peers. MADDSP surveillance confirmed ASD diagnosis of participants with a documented ASD classification by a professional, an ASD diagnostic billing code present in records, or ASD eligibility for special education services (Jarquin et al., 2011). Jarquin et al. (2011) found that Non-Hispanic African American children were 50% more likely to meet ASD eligibility criteria and not have a documented ASD diagnosis than their Non-Hispanic White peers.

Travers, Tincani, and Krezmien (2011) calculated ORs to determine the probability of a child being diagnosed with an ASD and also calculated the risk index

(RI), consisting of the percentage of students from a racial group with an ASD from 1998-2006. When comparing African American and White students, the differences in the RI increased every year from 2000 to 2006. By 2006, the RI for all culturally and linguistically diverse (CLD) students was three times lower than the combined RI and was less than half of the RI of White students (Travers et al., 2011).

Three studies utilized data from the National Survey of Children with Special Health Care Needs (NS-CSHCN), a cross-sectional, random-digit-dialed, computer-assisted telephone survey administered by the National Center for Health Statistics. Verification of the presence of an ASD was validated in NS-CSHCN by asking, "Has a doctor or other health care provider ever told you that [CHILD] has autism, Asperger's disorder, pervasive development disorder or other autism spectrum disorder?" (Heejo et al., 2015). If parents responded "yes" to the previous question, this follow-up question was posed "Does [CHILD] currently have autism or an autism spectrum disorder?" (Heejo et al., 2015).

Heejo et al. (2015) analyzed data from the 2009-2010 NS-CSHCN and found the prevalence of ASD in the sample was 15.3 per 1000 Non-Hispanic White children ages 3-17 and 10.4 per 1000 Non-Hispanic African American children ages 3-17. Montes and Halterman (2011) reviewed data from the 2005-2006 NS-CSHCN and found the presence of ASD in the sample (n=35,386) was 5.39% (95% CI, 5.01%-5.79%). Montes and Halterman (2011) also found no detectable difference in the prevalence of ASD based on race for African American and White children, (White 5.51%, African American 4.87%, $F= 1.60$; $P>.05$).

AGE OF DIAGNOSIS

Two studies focused on data pertaining to the metropolitan area of Philadelphia, Pennsylvania and discovered disparities in the age of diagnosis for African American children. Mandell, Listerud, Levy, and Pinto-Martin (2002) analyzed data from Medicaid records of eligible residents in Philadelphia County during the fiscal year 1999 and found that White children were diagnosed with ASD at an average of 6.3 years. Mandell et al. (2002) also found that White children entered the mental health system earlier than their African American peers. By age 5.5, half of the White children in the sample were diagnosed with ASD however 28% of the African Americans in the sample were diagnosed at that age (Mandell et al., 2002).

Mandell, Ittenbach, Levy, and Pinto-Martin (2007) reviewed data obtained from the Medicaid reimbursement claims in Philadelphia, Pennsylvania from 1993-1999 and found that the average age on the first visit for White children was 6.3 years old and for African American children 7.1 years old. Mandell et al. (2007) also found that African American children diagnosed with an ASD were three times more likely than their White peers to receive another diagnosis of ADHD, conduct disorder, or adjustment disorder first.

Emerson, Morrell, and Neece (2016) analyzed data and methodology reports from the 2011-2012 National Survey of Children's Health and found that the average age of diagnosis was 64.65 months which is approximately 5.38 years old. Based on the sample, African American children were diagnosed on average by 50.89 months old which was earlier than their White peers at an average of 68.24 months old (Emerson et

al., 2016). Based on this national survey, there are mixed results regarding the age of diagnosis for African American children with ASD which highlights a need to analyze these issues further to explain the conflicting research.

Diagnostic delays may also reflect differences in parental initiation of diagnosis, which could be influenced by the likelihood that African American parents do not feel like partners in their child's healthcare process. In the African American community, a mistrust of the medical establishment is validated through a longstanding history that still resonates today (Poussaint & Alexander, 2001). In both Angell and Soloman (2014) and Burkett et al. (2015) parents felt that physicians did not listen to their concerns and did not devote enough time to their child. These negative interactions with healthcare providers can influence the parents' willingness to seek medical advice and care for their child, including their decision to seek referral appointments with specialists.

SEVERITY OF ASD

When analyzing the data based on the severity of the ASD diagnosis, it is important to note that data on this variable was not adequately collected in all cases. The severity of an ASD diagnosis was classified in NS-CSHCN surveys by asking parents to describe their child's ASD as mild, moderate, or severe however parents were given no explanation of these terms (Heejo et al., 2016). Among children identified with severe ASD, 21.1% of the Non-Hispanic African American children were identified, and 14.2% of the Non-Hispanic White children were identified. Heejo et al. (2015) also utilized NS-CSHCN data and established that 50% of Non-Hispanic White children whose parents perceived their ASD severity to be mild/moderate had a later diagnosis compared to the

33.5% of Non-Hispanic African American children whose parents had the same perception.

Jarquin et al. (2011) utilized data from the MADDSP sample and determined ASD severity based on the presence of an Asperger's diagnosis or an autistic disorder diagnosis in the medical records. In 2013, the *DSM-5* removed the Asperger's Syndrome diagnosis to build the umbrella term, autism spectrum disorder. Children diagnosed with Asperger's Syndrome were intellectually capable, held an adherence to stereotypic routines that were often obsessive, and struggled with pragmatic language (Polirstok & Houghteling, 2006). This study found that Non-Hispanic African American children were more likely to have the more severe diagnosis of the two when compared to their Non-Hispanic White peers. Less than three Non-Hispanic African American children per surveillance year (2000, 2002, 2004, and 2006) had an Asperger's diagnosis however 28 Non-Hispanic White children per monitoring year had the same classification. Jarquin et al. (2011) also found that Non-Hispanic White children were more likely to receive an ASD diagnosis across all levels of severity but Non-Hispanic African American children were more likely to receive the most severe diagnosis.

FACTORS INFLUENCING DIAGNOSIS DISPARITIES

Durkin et al. (2010) analyzed ADDM data in 12 states and compared this to demographic data retrieved from the 2000 Census. They found an overrepresentation of ASD for Non-Hispanic African American children with lower SES. The percentage of Non-Hispanic African American eight-year-olds in the surveillance area living in poverty was 51.1%, and 36.1% had ASD ($p < 0.05$) (Durkin et al., 2010). In Durkin et al. (2010),

the percentage of Non-Hispanic African American eight-year-olds living with an adult with a Bachelor's degree was 16.5%, and 21.5% of those children had ASD ($p < 0.05$). Overall, 28.6% of eight-year-olds in the surveillance area were Non-Hispanic African American and 24.6 % of those children were diagnosed with ASD ($p< 0.05$) but only 15.7% of eight-year-olds in the U.S. were Non-Hispanic African American ($p< 0.05$) (Durkin et al., 2010).

Parents in Burkett et al., (2015) provided insight into cultural perspectives surrounding healthcare for their African American children with an ASD. Healthcare professionals may not be screening for ASD in African American children as quickly as they do for White families because of pre-determined understandings of how to assess parent concerns based on race. In Burkett et al. (2015) healthcare professionals noted the potential for a professional bias toward the diagnosis of the White child with ASD because this group is most often diagnosed. However, healthcare professionals in Burkett et al. (2015) also believed that it was more difficult for African American families with a child with ASD to access resources due to limited economic resources, knowledge gaps regarding ASD and the utilization of different social networks than their White counterparts.

Emerson et al. (2015) found that physicians were less likely to refer African American children to specialists and after referral African American patients were not addressed with the same rate or speed as patients of other races. Less frequent referrals to the necessary health care professionals could influence delayed diagnosis and delays in

treatment, both of which can be detrimental to the patient. With the diagnostician type differing by race, this puts more pressure on PCPs to resolve issues related to diagnostic timing because these factors impact African American children at a higher rate. A problem affecting diagnostic timing could be the physician's knowledge of the presentation and treatment of ASD and how this influences the ability to diagnose patients adequately. The medical community needs to address these differences to provide culturally relevant care to African American families; however, there is a lack of research regarding the African American parent's experience with ASD. There must be changes in healthcare practices and the expectations of practitioners to account for socio-cultural misunderstandings that influence the diagnosis and treatment. It is essential for evaluators to take these socio-cultural factors into account when diagnosing African American children with an ASD, writing their reports, and interacting with the families following diagnosis and a way to do this would be through family-centered care.

Family-centered care is an initiative supported by the American Academy of Pediatrics and focuses on the integration of patient and family-centered care across healthcare settings through high-quality provider interactions. These interactions include actively listening to parents, sensitivity to the cultural values and experiences of the family, and providing information about the child's treatments or condition in a culturally sensitive manner

(Committee on Hospital Care and Institute for Patient and Family Centered Care, 2012).

Magaña, Parish, and Son (2015) analyzed both the 2005-2006 and 2009-2010 NS-CSHCN and found in 2006, African American parents were less likely (82%) than White parents (86%) to report the healthcare provider listened carefully to the parent. In 2010, however, African American parents were 75% less likely, and White parents were 85% less likely to report the same question illustrating that parents did not feel the provider listened more over time. Magaña et al. (2015) also found in 2006 and 2010, White parents were 84% likely to believe the provider helped them feel like a partner but African American parents were 78% and 74% likely to share that feeling in 2006 and 2010 respectively. Only 64% of African American parents in 2006 reported the provider spent enough time with the child during the visit and 59% of African American parents agreed with this statement in 2010 compared to 78% of White parents in 2006 and 75% of White parents in 2010 (Magaña, Parish & Son, 2015). When asked if the provider was sensitive to the family's values and customs 88% of White parents in 2006 and 87% in 2010 agreed, but 78% of African American parents in 2006 and 80% in 2010 agreed (Magaña et al., 2015).

African American parents in Montes and Halterman (2011) shared similar feelings regarding receiving family-centered care and were more likely to respond to the statement, "My doctor does not help me feel like a partner in care" (Wald F= 3.44; P> .05). African American parents with a child diagnosed with an ASD had five times greater odds of stating that doctors did not spend enough time with their child (OR 5.05, 95% CI, 3.30–7.72) (Montes & Halterman, 2011). Furthermore, Montes and Halterman (2011) found that parents of African American children with an ASD had three times

greater odds of reporting that doctors were only occasionally sensitive to their values and customs (OR 3.35, 95% CI, 2.05–5.47) or occasionally provided specific information (OR 3.07, 95% CI, 1.98–4.76). African American parents with a child with an ASD diagnosis also had two times greater odds of reporting that doctors helped them feel like a partner in care sometimes or never (OR 2.42, 95% CI, 1.51–3.90), and that they were listened to carefully only seldom or never (OR 2.36, 95% CI, 1.48–3.77) (Montes & Halterman, 2011).

INTERPRETING MIXED FINDINGS

There were mixed findings from national studies determining the age of diagnosis for African American children with ASD and most studies found these children were diagnosed later than their White peers. A lower prevalence of ASD was seen in African American eight-year-olds in the low SES category in Durkin et al. (2010). In the sample area, the majority of African American children had a lower SES which impacted the overall prevalence.

Socioeconomic status (SES) is an essential factor to consider when evaluating the age of diagnosis in African American children because children from families with a lower SES are more likely to be diagnosed by a PCP, making access to healthcare a factor. Having a consistent source of medical care and the ability to receive routine medical supervision is less likely to be attainable for families of a lower SES (Devoe et al., 2007). Broder-Fingert et al. (2013) found that minority parents may have socioeconomic, scheduling, and transportation barriers that impact their ability to visit

healthcare specialists. African American parents with a lower income can be intimidated in the medical setting due to convoluted jargon and differences in worldviews (Reichard, Sacco, & Turnbull, 2004). African American parents with a low SES may have increased barriers preventing them from accessing information and healthcare professionals to obtain an accurate diagnosis for their child because of the quality of the patient's health insurance.

Liptak et al. (2008) reported that 98% of children with autism had health insurance as compared to 91% of children without ($p < .001$). Of the children with health insurance, 37% of children with autism had Medicaid/State Children's Health Insurance Program (SCHIP) versus 30% of children who did not have autism ($p < .001$) (Liptak et al., 2008). The type of health insurance the patient utilizes can impact the age of diagnosis because participants in Mandell (2005), (2007), and (2009) were Medicaid-enrolled patients and African American children were diagnosed with ASD at least 1.5 years later than their White peers. Therefore, SES could impact a patient's ability to have access to adequate health care, thus delaying their child's diagnosis.

THE VALUE OF THE AFRICAN AMERICAN PARENT

African American parents are sometimes perceived negatively by clinicians that provide services for their families. For instance, African American parents in Gourdine, Baffour, and Teasley (2011) reported that the clinician perceived them as uneducated, seemed to have a cavalier attitude about the expectations of the child and they felt clinicians were pressuring them to agree with their methods of treatment or assessing the

child. These perceptions negate the unique and valuable cultural experiences that African American families hold and more research is needed to take advantage of this knowledge to change attitudes entirely.

CONCEPTUAL FRAMEWORK

This research was examined using three theories including cultural capital which refers to the collection of symbolic elements such as skills, tastes, mannerisms, material belongings, credentials, etc. that one acquires through being part of a particular social class (Bourdieu, 1986). Cultural capital is a significant source of social inequality because some forms of cultural capital are valued over others, and can help or hinder one's social mobility as much as income or wealth (Bourdieu, 1986). Analyzing the participants' responses regarding the path to obtain an ASD diagnosis for their child can determine if cultural capital was utilized, disregarded, or not present in the process. Due to disparities for African American children with ASD, it is imperative to understand if race and ethnicity have a role in the diagnosis process and African American parents can be crucial resources to enrich this understanding. Bourdieu's theory of cultural capital illustrates how the use of symbolic capital can influence cultural performances which can be transistors of power (Shapiro, 2009). Cultural capital interacts with power and access which both have a complicated position in disability diagnosis; however, there is limited research establishing the importance of cultural capital for individuals with disabilities and their families.

One way that cultural capital is present in the lives of parents is through resilience; family resilience is the "characteristics, dimensions, and properties that help

families resist breakdown in the face of change and adapt to stressful obstacles (M. A. McCubbin & McCubbin, 1988). Family resilience is not one specific set of strengths but instead an alternating passage, unique to each family and circumstance. A family's response to a challenging situation depends on the sociocultural and developmental context, the unique interaction of risk and protective factors within the family, and the family's perception of the challenge (Greeff & Nolting, 2013). Responses to a situation such as having a child diagnosed with ASD need to be understood with these factors in mind to assess the parent's experience fully.

M. A. McCubbin and McCubbin (1996) introduced the resiliency model of family stress, adjustment, and adaptation, which provides a theoretical framework outlining the processes involved in a family's response to a stressor. When faced with a stressor a family must adjust to incorporate the impact of this concern while simultaneously maintaining family balance. Realizing or being told that your child is not developing at the same rate as his or her peers is a significant stressor for a parent. Understanding how African American parents overcome, adjust, and persevere during the ASD diagnosis process can provide insight to lead to policy and procedure changes potentially.

DisCrit

The previous theory provides a framework to analyze the findings based on cultural and sociological factors within the family; however, disability also has a significant impact on this research. There is a need to employ dis/ability critical race Studies (DisCrit) which "theorizes about the ways race, racism, dis/ability and ableism are built into the interactions, procedures, discourses, and institutions of education, which

affect students of color with dis/abilities differently than White students with dis/abilities" (Annamma, Connor, & Ferri, 2013). According to responses from participants in Williams (2007), African American parents perceived the impact of cultural underpinnings throughout the diagnosis process. For instance, one parent reported, "My observation has been that many of these students are in special education because of a lack of understanding of their culture. When a kid comes in acting very energetic and seems to be out of control, you throw them in special ed just to get rid of them" (Williams, 2007, p. 255). Parents perceived their children being assessed differently because of sociocultural factors and comparisons to their White peers. Another participant response from Williams (2007), provided an account of a flawed evaluation a parent received, "When I got the report back, I was furious. It was a typical white woman's view of an African American man. It said he was depressed, that he could do harm to himself" (p. 254). Parents knew that the clinicians negatively perceived their children and this impacted the evaluation. The experiences of these parents highlight how interactions and procedures affect students of color because race and racism are woven into the diagnosis process.

DisCrit attempts to understand how issues of ableism and racism interact with discriminatory structural practices to impact the daily lives of children of color with disabilities (Annamma, Connor, & Ferri, 2013). These discriminatory structural practices are utilized to create channels of power for clinicians, service providers, and school personnel. With this power, a student of color's disability status can be used to justify unequal treatment and segregation (Annamma, Connor, & Ferri, 2013). There is an

awareness of the power that clinicians hold due to their expertise; however, the power that parents possess is often disregarded. Even with discriminatory practices, racism, and other factors hindering African American parents they can obtain an ASD diagnosis for their child. This ability to withstand the impact of these forces highlights the resilience of African American families; therefore understanding how parents navigate the diagnosis process can bring awareness to the power they possess.

Cultural reciprocity

African American parents with a child with a disability have to navigate race, cultural, and disability simultaneously to support their child; however, there needs to be a focus on the impact of the clinician. When interacting with clinicians parents must overcome cultural blindness which Kalyanpur and Harry (1997) defined as when professionals do not engage in "the process of introspection and inquiry that leads to questioning taken for granted beliefs" (p.488). Cultural blindness impacts daily interactions because individuals are not aware how behavior is rooted in one's culture and that blindness can adversely affect a clinician's communication with families. When interacting with families, service providers must be mindful of the values and beliefs that impact the decision-making process. Active engagement with families requires an in-depth assessment of one's values and open discussion with the family to understand their values.

To remedy the adverse effects of cultural blindness, Kalyanpur and Harry (1997) argued for the need of cultural reciprocity. Cultural reciprocity "enables professionals to develop collaborative relationships with families from culturally diverse backgrounds by

becoming aware of the assumptions underlying both their and the families' responses to the child with disabilities" (Kalyanpur & Harry, 1997, p.489). The four-step process to developing a culture of reciprocity begins with the need to address your values and how these values impact the professional recommendations you present to the family. Secondly, attempt to identify the family's perspective and assess how this perspective may differ from your own. Thirdly, create an opportunity for an open dialogue to explain your recommendations and listen to the families' concerns. Finally, establish a compromise with the family so that your recommendations for the child are appropriate and support the families' values. Cultural reciprocity is a means to allow the family an opportunity to have an active voice in the dialogue.

The need for collaboration between culturally and linguistically diverse families and the culture of reciprocity can also be applied to diagnosis practices for children from CLD backgrounds. Fuller and Coll (2010) discussed how parents hold the key to ethnically bounded socialization goals as well as the cultural model or behavior scripts they follow. By collaborating with families, service providers gain valuable insight into the culturally influenced behavior scripts that parents instill in their children. To stop cultural blindness and the impact it has on the assessment and identification of CLD students, this open dialogue between families and service providers is essential to ending assumptions about the behavior of African American students.

Behavior should be seen in relation to the culture of the student observed because the issue of behavior is something that is culturally nuanced especially with interpersonal communication style. Artiles (2010) discussed the placement data suggesting that

African Americans and Native Americans are overrepresented in high-incidence disability categories at the national level because diagnoses of these disabilities are judgmental and rely heavily on the professional clinicians' decisions. Incorporating the culture of reciprocity into the diagnosis process will create a dialogue between the families and the practitioners. By encouraging practitioners to evaluate their own cultural biases and then collaborate with the families during the assessment process, misconceived notions regarding the behavior of minority students could be understood within a cultural context. Sharing the experiences of African American parents through the diagnosis process can inform clinicians of ways to better support the culture of reciprocity. The experiences of African American parents can serve as a tool to call for change in practices and ultimately highlight the value of the parent's knowledge.

Chapter 3: Methods

This study focused on viewing the ASD diagnosis process from the African American parent's perspective to attempt to understand their reality. The ontological belief that there is no objective social reality, but instead multiple realities are the foundation of the interpretive paradigm (Bailey, 2007). These various realities exist due to numerous factors that shape one's reality such as race, ethnicity, and SES and it is imperative to examine these realities in attempts to better understand the ASD diagnosis process for families. The methodology of the interpretive paradigm typically includes interactions with and observations of participants in the setting which directly connects with the use of case study methods (Bailey, 2007).

The epistemological belief rooted in the interpretive paradigm is that what is learned in research does not exist independently of the researcher, which is why my positionality as a researcher must be carefully examined and monitored throughout this study (Bailey, 2007). Operating under the interpretive paradigm suggests that knowledge is socially constructed through language and interaction, and reality is connected and understood through society's cultural and ideological categories (Tracy, 2012). Accepting the interpretivist paradigm as the lens to frame my qualitative research brings specific implications accompanied with this choice including, "using an interpretive lens may also lead to the call for action and transformation – the aims of social justice – in which the qualitative project ends with distinct steps of reform and an incitement to action" (Creswell, 2012, p.24).

The majority of research regarding African American diagnosis disparities focuses on findings from large national datasets, and there is limited research to examine the diagnosis process from the parent's perspective. This study examined how the participants navigate and construct their realities as a parent of a child with ASD to highlight racial disparities and how parents overcome. The purpose of this study was to provide the reader with an empathetic understanding of the participants' experiences and an increased awareness of the multiple meanings given to the process of obtaining an ASD diagnosis by parents. Hopefully, this understanding will lead to a call for action to change diagnostic procedures and transform how clinicians interact with African American parents.

METHODOLOGY

For this study, the unit of analysis was a case or a bounded system, a sample of African American parents with a child diagnosed with ASD (Merriam & Tisdell, 2016). The case study is "an in-depth description and analysis of a bounded system" (Merriam & Tisdell, 2016, p. 37). This in-depth analysis of the bounded system is needed to research the narrative surrounding obtaining an ASD diagnosis for a child. Through the use of case study, the flexibility in data collection methods allowed the participants' voice to shape the findings and recommendations that other methodologies would not provide such as randomized control trial or single subject research.

Case studies must be particularistic, heuristic, and descriptive (Merriam, 1998). Particularistic because the focus is on this sample of African American parents with a child diagnosed with ASD because these cases may represent parents that have

successfully obtained an accurate diagnosis of ASD for their child despite diagnosis disparities. Heuristic because this research can enlighten the reader on the journey to diagnosis for African American parents and their children. Descriptive in an attempt to provide a thick description of the experiences of this sample of parents that is a complete holistic view of the case.

This instrumental study sought to provide insight into a broader issue, the disparities in ASD diagnosis for African American children (Merriam & Tisdell, 2016; Stake, 2005). Structuring this as a case study was essential to enhance external validity and the generalizability of the findings. An instrumental case provides a thick description of a particular group and is chosen carefully to ensure that the case will yield fruitful conclusions pertaining to the research question (Stake, 2005).

POSITIONALITY

As a researcher, it is vital to address positionality because the process of observing can impact those observed and the researcher needs to identify and account for those effects (Merriam & Tisdell, 2016). Sharing a racial identity with the participants initially drew me to focus on their experiences and my previous position as a middle school special education teacher is why the focus is on children with ASD. However, despite the shared racial background and experience educating children with ASD, I consider myself a complete outsider because I am unable to relate to the participants' experiences personally.

As I introduced myself to participants, I unpacked my positioning as a former teacher for self-contained students with ASD, an educational diagnostician that identifies children with ASD, a former coordinator of a parent support network and as a doctoral student in the special education department with a multicultural focus. Establishing a rapport with the participants was essential to me and transparency about my past experiences hopefully further expressed to parents why I am conducting this research. Depending on the interaction during the interview, I revealed or withheld experiences, for instance, my working-class upbringing or my current position as an Elementary Special Education Coordinator for a school district. As a researcher, my primary concern is providing the participants with a comfortable space to share their ways of knowing and I did not want my persona to impede upon their space.

SETTING

The participants were sought after for living in the top fifteen states with the most extensive African American populations according to the 2010 U.S. Census: Mississippi, Louisiana, Georgia, Maryland, South Carolina, Alabama, North Carolina, Delaware, Virginia, Tennessee, Florida, Arkansas, New York, Illinois, and New Jersey. Using purposeful sampling, the participants were found by sharing an informational flyer via email through ABA therapists, parent support groups, and community-based organizations that support children with disabilities. Purposeful sampling was employed to create an information-rich case that incorporates data from a sample that can provide the most to learn from (Patton, 2015). The parents that participated currently reside in South Carolina, Georgia, Florida, California, Maryland, and Virginia.

The decision was made to reach out to organizations in these states in hopes of being able to reach the most African American families possible. African Americans are less likely to participate in research for many reasons such as fear, a lack of information about research and its purpose, and a general mistrust of research (Hughes et al., 2017). Two potential facilitators of African Americans participating in research are recognizing the potential benefits of the study and giving back to the community (Hughes et al., 2017). When discussing the research with potential participants the lack of research in this area and the importance of hearing the families' perspectives were mentioned to activate these facilitators.

PARTICIPANTS

The participants were parents or guardians that self-identify as African American and have a child diagnosed with ASD. For this study, the term parent refers to the child's legal guardian and included mothers, fathers, stepfathers, stepmothers, adoptive parents and extended family members that are the child's guardian. Foster parents were excluded from eligibility because the child's case manager would make significant health decisions for the child instead of the foster parent. Parents with a child diagnosed with ASD over five years ago were excluded because ideally, the recent diagnosis would lead to the most fulfilling recollection of the process. The child must have an ASD diagnosis that can be confirmed by analyzing the archival data provided by the parent including the most recent evaluation. There were 13 participants; one father, one grandmother, and eleven participants were mothers. There were no inclusion criteria set based on income,

education or marital status and as a result, participants came from a variety of backgrounds and states.

DATA SOURCES

The following three sources were used to collect data: semi-structured interviews (see Appendix A), the ASERT Parent Needs Assessment (see Appendix B), and archival data obtained from the child's recent ASD evaluation. Data collection began in May 2017 and concluded in December 2017.

Interviews

Interviews were necessary for this instrumental case study because of the interest in past events that are impossible to replicate such as those pertaining to the ASD evaluation process (Merriam, 2009). The interviews were semi-structured because this method assumes that participants define the world in flexible ways and this provides flexibility to capture their ways of knowing (Merriam & Tisdell, 2016). Semi-structured interviews allow the researcher to respond to the worldview of the respondent and new ideas that emerge through the interaction (Merriam, 2009). Due to my positionality as a researcher and the theoretical framework employed I am aware that the participants presented their socially constructed reality and structured interviews would not allow adaptability to this circumstance. The semi-structured interviews were guided by a set of questions and ideas that did not have to be presented in a particular order or use specific wording. Interviews were conducted once with each participant and lasted between 30 minutes to an hour. Interview questions addressed the following areas: discussing the

initial symptoms, an overview of the evaluation process, and perceptions of the interaction with evaluation professionals. The interviews were digitally recorded and transcribed using a transcription application.

Parent needs assessment

The participants completed an ASERT Parent Needs Assessment to collect data including demographic information, identify ways the child's ASD diagnosis has impacted the family, and parent satisfaction with services. The first three pages of the assessment ask about demographic information such as race, ethnicity, yearly income, age of the children, type of health insurance, and the diagnoses of the children. The next few pages are for parents of a child that has been hospitalized for behavioral or psychiatric reasons. Questions about the hospital stay include the reason for admittance and satisfaction with the hospital stay. The next page of questions are about the child's current living arrangement, school discipline, long-term plans for the child, and current interventions or therapies. The assessment then asks about the current IEP if applicable, satisfaction with the IEP and the child's current level of functioning. The next pages inquire about the siblings, their ages, if they have any diagnoses, and their behaviors when compared to same-age peers. The next section asks about the satisfaction with the oldest child's current care such as any limitations that prevent the family from accessing dental care or health care, and if the current interventions and therapies are meeting the needs of the child and family. The last page asks parents to provide the contact information for any service providers that they would recommend to other families. This assessment was created by the Autism Services, Education, Resources and Training

Collaborative (ASERT). ASERT is an organization in Philadelphia that conducted the Pennsylvania Autism Needs Assessment in 2010 and collected over 3,500 surveys to determine the needs of families with children with ASD. The needs assessment was presented to parents via mail or email to complete following the interview.

Archival data

The child's ASD evaluation report was the archival documentation requested by the participants. Analyzing this document was imperative due to findings presented in Angell and Solomon (2014) which reviewed health-records data from African Americans to examine themes and patterns that emerged from the data. This study found that there was variability in how parent-reported information was incorporated into the reports. For example, one child's mother was described as both unemployed and a full-time homemaker in different evaluation reports, "The reports and descriptions that I could not even stand reading for years because of the description of how the doctor saw me" (Angell & Solomon, 2014, p.52).

There was also variation in the descriptive nature used to address the child, “an adorable 37 months old boy of African descent whose interests are toy cars and trucks” or “a 37 months old African American male” (Angell & Solomon, 2014, p.52). The diagnostician writing the report is providing a description of the parent and the child that will be read by other professionals which is why family-centered phrasing would portray families how they see themselves.

The evaluation provides relevant data regarding patterns that make exist regarding how African American parents are perceived, the diagnosis including the child's age at

assessment, analysis of the evaluation procedures, and recommendations from the evaluator. As an educational diagnostician certified to diagnose children with ASD in the state of Texas and with this background, I also analyzed the quality of the diagnosis based on DSM-V and IDEA standards. Once in possession of these documents, the authenticity and accuracy of the data were verified using questions established by Guba and Lincoln (1989). The objective of this study was to understand the ASD diagnosis process for African American parents and these documents provided critical information regarding the diagnosis process as the final written representation of ASD. Understanding these documents and their role in the participants' reality is important and can bring clarity to these cases.

Data Analysis

Triangulation, is a method used to strengthen a research design by utilizing multiple data sources (Denzin, 1970). Triangulation allows researchers to, "make use of multiple and different sources, methods, investigators and theories to provide corroborating evidence" (Creswell, 2012, p. 208). Triangulation was essential for this study to give insight to the experiences of families, to increase validity, and to seek comprehensive data. The data was analyzed by taking it apart, searching for patterns, and then putting it back together in a meaningful way (Stake, 2005). The goal throughout the analysis was to find a sense of correspondence or consistency to ultimately create naturalistic generalizations (Stake, 2005). By analyzing data from the primary data sources including the interviews, parent needs assessments and archival data, this study was able to uncover a richer understanding of the parents' experiences. The

incorporation of multiple methods of data collection added value and minimized measurement bias.

The method of coding the interviews was inductive because, "the researcher is open to what the site has to say rather than determined to force-fit the data into pre-existing codes" (Miles, Huberman & Saldana, 2014, p. 81). As a researcher that is not a parent of a child with special needs, inductive coding was chosen to avoid using preconceived codes to shape the research. The coding was in vivo coding, "using words or short phrases from the participant's language in the data record as codes" (Miles, Huberman & Saldana, 2014, p. 74). In vivo coding was used because the participants repeated similar phrases and themes throughout the interviews and it was essential to support the participant's experiences by using codes in their own words. These repeated phrases were documented and organized based on frequency. Any phrase that was repeated 5 or more times represented a theme found in the interviews.

The parent needs assessments were reviewed and the answers were categorized into a spreadsheet to document data including demographics, parent needs, and the child's level of functioning. These responses were used to provide background information on the participants and validate responses from the interviews and the archival data. For example, in the interview parents were asked when they first noticed that their child was behaving differently to give background information on how long the concerns were present. The parent needs assessment also asked at what age did you begin having concerns which presented another data point to confirm when the concerns arose. In the archival data, the parents were given the opportunity to report their

concerns in the assessment through interviews which also presented a data point regarding parent concerns.

The archival data were the ASD evaluations that the parents submitted. These were examined to verify the diagnosis of ASD, search for discriminatory language about the child or family, and to confirm any data presented from the interviews. The discriminatory language was evident in Angell & Solomon (2014) during a review of the medical records of African American and White children with ASD. This language varied based on race and African American parents were referred to in a discriminatory manner to include the discussion of their educational status or socio-economic status. In this study, I read the ASD evaluations to determine the presence of similar language discussed in Angell & Solomon (2014).

The validity of this study was strengthened by the presence of consistent findings evident in the themes from the interviews, confirmable findings that represent similar findings from the literature, credible findings due to the cross-checking during triangulation, and dependability was supported through explicit documentation of the research methods and data analysis.

Protection of Human Subjects

A proposal was submitted to the researcher's Dissertation committee, and upon the approval of the committee, the application of the proposal was sent to University of Texas at Austin Institutional Review Board (IRB). The IRB reviewed the application to ensure the protection of human subjects and the proposal met IRB criterion. In addition,

the informed consent form was given to each participant before participation in the study. This consent form explained the purpose of the study, ensure confidentiality, and explain that participation is optional and can be rescinded at any time. All documents collected to be used as archival data and parent needs assessments will remove identifying information of the participant and the child. These documents and the completed parent needs assessments will be kept in a locked box in the researcher's private office that is also locked.

Chapter 4: Results

Description of Parent Experiences

The first research question that guided this study was how do African American parents describe their experiences related to obtaining a diagnosis for their child with an ASD? To answer this question, twelve semi-structured interviews were conducted with parents of African American children with ASD that focused on the diagnosis process. The interviews provided insight into the parent's experiences obtaining an ASD diagnosis for their child through various methods such as child find, developmental pediatricians, clinical agencies and child psychologists. The semi-structured interview questions were designed to explore the diagnosis process specific to the child. Having participants from various states with different methods of diagnosis, broadened the findings on how these parents described their experiences.

The participants

Carol is a mother from South Carolina that has completed some college and utilizes Medicaid for health care services. She is a widow that makes between $20,000-$39,999 yearly, identifies as an African American and has a nine-year-old son. Her son with ASD has six siblings, and none of them have been diagnosed with ASD. Her son's primary diagnosis is Autism, and he also has a current diagnosis of Developmental Delays which he received before his ASD diagnosis. Carol noticed that her son was developing differently around the age of 1 years old which is also the same age that he received his ASD diagnosis from a psychologist. Her son has an IEP, she feels it addresses her concerns, and he currently receives speech therapy. Her son can do the

following independently: eat, use the restroom, feed himself, dress himself, indicate when he is sick, and request things he needs or wants.

Janet is a mother of two from South Carolina that has completed some college and utilizes private health care to pay for health care services. She has a seven-year-old son whose only diagnosis is ASD, and she has another child that does not have ASD. Janet and her son both identify as African American. She is divorced and makes between $80,000-$99,000 yearly. Her son was diagnosed with ASD at the age of 3 years five months by an IEP team, but she first became concerned with his development at age one year six months. Her son receives speech and occupational therapy, social skills training and one to one paraprofessional support, has an IEP, she feels the IEP address all of her concerns. Her son can do the following independently: eat, use the restroom, indicate when he is sick, and request things he needs or wants.

Brittany is a mother of a four-year-old son diagnosed with ASD and Global Developmental Delay. Brittany does not have any other children and currently resides in Georgia where she makes under $20,000 yearly. She identifies as African American and Latina, has completed some college, has never been married, and utilizes Medicaid for health care services. Her son was diagnosed at age three years three months by a PCP and Brittany first became concerned with his development at age 3. Her son has an IEP, she feels the IEP address all of her concerns, and he currently receives speech services. Her son can do the following independently: eat, dress himself, use the restroom, and request things he needs or wants.

Teresa is a mother of an 11-year-old son that is currently diagnosed with ASD,

Developmental Delay, Learning Disability, and Intellectual Disability. She is a mother of four, and none of her other children have ASD. Teresa lives in Florida, has never been married, and has completed a graduate degree. She currently makes under $20,000 a year, identifies as African American, uses Medicaid to cover health care services, and first became concerned with her son's development at age two years three months. He was diagnosed by a Developmental Pediatrician at age six years one month. Her son has an IEP, she feels the IEP address all of her concerns, he currently receives speech and occupational therapy, social skills training, one to one paraprofessional support, and case management services. Her son can do the following independently: eat, dress himself, use the restroom, request things he needs or wants, and indicate when he is sick.

Darrielle is an African American mother of a daughter that is five years and two months old and is currently diagnosed with ASD but was previously diagnosed with Developmental Delays. She is married and living with her daughter's father. Darrielle has completed some college, makes between $20,000-$39,999 a year, and utilizes grants and Medicaid to cover health care expenses. Darrielle did not indicate an age when she first became concerned with her daughter's development, but a psychologist diagnosed her at one year old. Her daughter has an IEP, and she does not believe the IEP addresses her concerns. Her daughter can feed and dress herself, request things she needs and wants and can indicate when she is sick.

Caitlin is an African American mother that has never been married and currently lives in Virginia with her twin sons that are three years six months old. Both of her sons have ASD and are also presently diagnosed with Developmental Delays. Caitlin

identifies as African American, makes between $20,000-$39,999 yearly, has a college degree, and utilizes Medicaid to pay for health care services. A Developmental Pediatrician diagnosed her sons at age 2, and her concerns were initially raised at age one year four months. Her sons are receiving interventions for self-injurious behaviors, aggressive behaviors, running away, and toileting. Her sons have IEPs, she feels their IEPs address all of her concerns, and they currently received speech and occupational therapy services.

Xavier is a father of a twelve-year-old son and a seven-year-old daughter both diagnosed with ASD. He makes over $100,000 a year, utilizes private health insurance, and feels that the IEPs for his children address his concerns. His daughter is diagnosed with ASD, and a learning disability and his son is diagnosed with ASD and Developmental Delays. His children receive occupational and speech therapy and extended school year services. He has a college degree, resides in Maryland and was married to Ophelia. Ophelia also participated in the same interview with Xavier; however, Xavier completed the parent needs assessment.

Courtney is a mother of an eight-year-old son currently diagnosed with ASD and Intellectual Disability. Her son was previously diagnosed with Intellectual Disability, ADHD, and Developmental Delay before obtaining the ASD diagnosis. Her son has an IEP and Courtney does not think the IEP fully addresses her concerns. Courtney lives in Florida, is married and living with her son's father, and has a yearly income of $40,000-$59,000. She utilizes Medicaid to pay for health care expenses, and her child receives speech and occupational therapy, social skills interventions, and

extended school year services. Her son is an only child and can independently eat and dress himself, request things he needs and wants, and use the bathroom.

Francene is a mother of two sons that lives in South Carolina and has never been married. She has a yearly income of under $20,000 and utilizes Medicaid to pay for health care services. Francene did not finish high school but is currently pursuing her GED through online courses. One of her sons has ASD is also diagnosed with ADHD which was a diagnosis he had before his ASD diagnosis, receives speech therapy, one to one paraprofessional services, extended school year services and social skills supports. Francene's son has an IEP, and she does not think it adequately addresses her concerns. Her son can do the following independently: eat, dress himself, use the restroom, request things he needs or wants, and indicate when he is sick.

Raksha resides in Georgia, is currently married, has a graduate degree, and makes $40,000-$59,999 yearly. She utilizes private health insurance and has two children. Her seven-year-old son has ASD and is also currently diagnosed with ADHD and Developmental Delay. Before obtaining an ASD diagnosis, he was diagnosed with Developmental Delay. Her son has an IEP, and she does think it addresses her concerns. He receives speech therapy, occupational therapy, and a one to one paraprofessional aide. Her son can do the following independently: eat, dress himself, request things he needs or wants, and indicate when he is sick.

Tara lives in California, utilizes Medicaid and grants to cover health care expenses, and is married to her children's father. She has two children, and her six-year-old son is diagnosed with ASD and receives speech and occupational therapy, a one to

one paraprofessional aide, and social skills services. Her son has an ASD diagnosis and was previously diagnosed with Developmental Delay. Tara's annual income is $20,000-$39,999, and she completed a college degree. Her son has an IEP, but she does not feel that it addresses her concerns. Her son can do the following independently: eat, dress himself, use the restroom, request things he needs or wants, and indicate when he is sick.

One participant was a widow, three were separated or divorced, four were married to or living with the child's parent, and four have never been married. Seven participants utilized Medicaid and four utilized private health insurance; however, two parents also reported using grants for children with ASD to pay for some of the child's therapeutic and medical needs. Seven participants had a household income of under $39,999 per year, two participants made $40,000-$59,999, and the household income of three participants was over $80,000. Six participants attended some college and two were pursuing their college degree at the time, one participant did not finish high school, three had college degrees, and two obtained graduate degrees.

Theme: "something's not right"

Participants were asked during the interviews when they noticed that their child was behaving differently and shared experiences regarding what they noticed but at the time they did not identify as ASD characteristics. The purpose of asking this question was to try to understand which behaviors seemed alarming to the parents in this sample and what initiated the ASD diagnosis process. To get a glimpse of how the participants in this study were able to navigate the diagnosis process is valuable because families may struggle during the collaboration effort with service providers. Collaboration between

families and evaluators can be hindered by countless barriers that impact culturally and linguistically diverse families such as the feeling of powerlessness. Kalyanpur & Rao (1991) discussed the "dynamic of power" and how "professionals made the mothers confront their powerlessness in a system that gave credence to the service providers' opinions over theirs" (p.528). In this study, nine parents shared an experience connected to knowing that something was not right with how their child was developing. However, with this knowledge participants were unsure how to proceed and did not know when to discuss this information with the pediatrician. With the presence of a "dynamic of power" it is essential to examine the collaboration between the participants and the medical providers to determine how parents navigate this process.

Participants in this study discussed "something's not right" during the interviews which presents the finding that the participants lacked the specific knowledge regarding ASD characteristics however, they did have valid suspicions regarding their child's development. These suspicions whether they were about sensory observations or comparing the child to other children, were valid even without the label of ASD characteristics. The participants' initial knowledge about ASD characteristics was limited however, with this information the parents either sought help for their child through the health care system or were guided by the health care provider. Participants opened up about the relationship with their child's pediatrician which gave insight to the physician's role in each diagnosis experience. This role varies amongst the encounters shared; however, Teresa was warned by her son's doctors to monitor his progress because he was born prematurely:

> When he was born, like I said prematurely, they just kept telling me to keep an eye on it because he is going to be developmentally delayed. So he kept having cold and ear problems. So we had tubes placed in his ears. About around two and a half he just kept pointing at everything, not using any words and I was like okay something's not right

This mother heeded the warning from the doctors and watched her son's development carefully as he began to have difficulties with his ears. Her son was having problems with ear infections and was not making vocalizations which initially led the parent and doctors to think that placing tubes in his ears would rectify the situation. After this procedure, her son was still not making efforts to communicate verbally. She realized that something's not right because she expected the ear tubes to be the answer and began seeking medical help for her son which led to a diagnosis of ASD.

Other parents were informed by their pediatrician that their child was not meeting milestones after describing the progress that the child was not making. Caitlin has twin sons with ASD, and she shared what initially alerted the pediatrician that her sons may need speech services or testing:

> They weren't necessarily trying to talk or babble. We thought it was because they were still using their pacifiers. We brushed it off, but the doctor did mention that they weren't making those vocalizations and weren't at least trying to talk. That was our first clue to it, just basically them not trying to talk or communicate with us.

This parent discussed that she and her husband brushed off the fact that their sons were not communicating because they believed that they eventually would begin talking on their own. Upon sharing this information with the pediatrician, they were informed that this was a more significant concern than initially perceived. The pediatrician's role in this situation was to emphasize the significance of meeting developmental milestones

which led to further evaluations.

Several parents observed their child's behavior around the children of family members or friends and were able to notice that something was different. Janet noticed that her son was not interested in interaction with his peers, "like if we went to a party, he wasn't the kid who would sit with the rest of the kids at the table." Brittany compared her son to her nieces and nephews, "I noticed some things with me only having one child. All I could compare is like some of my nieces and nephews."

Another participant, Francene, observed her son behaving differently than typical children his age but was unsure of what to do with the information. This mother observed behaviors from her son that made her take notice which eventually led her to do some research however she did not initially share this with the pediatrician:

> When he started sitting, like he could sit up in the high chair, and I put him in there, he would bang his feet on the high chair, like really hard. Like I don't know if I ever said anything to the doctor about, it was like, this is kind of weird stuff. Like it feels like it should hurt. He hits his feet on stuff hard.

She realized that her son enjoyed hitting his feet on the chair and that he did it so hard it surprised her that he was not hurt. She began to do research online which led her to seek out a psychologist and occupational therapist which led her to pursue further evaluations for her son. The importance of doing research was apparent because once parents knew that something was not right, they began to seek information on ways to best support their child.

Theme: "if I just knew more"

Participants felt the need to do more research on ASD because they felt

unprepared to handle the challenges affecting the child. During the interviews the desire to acquire the knowledge necessary to support the child became evident through the theme "if I just knew more." This desire became evident for parents during different phases of the ASD process and participants took on this mission with a variety of vigor and determination. This theme presented the following finding, parents had an awareness of the needs of the child and were also aware that they needed to acquire the knowledge required to effectively navigate the ASD process for their child.

For the parents that noticed that their child was not meeting milestones and behaving differently than other children, they sought to find out more. Courtney shared her experience of when she began noticing that her son had challenges:

> I think if I just knew more about what was going on. If I asked more questions, I think that would have done it, if I asked more questions. I started doing a lot of research myself, and when I moved back to Florida and got him into a program here, his Pre K teacher did notice right off hand we needed to have him tested for autism. He was three, and I was like, okay, and just started researching autism

This need to research ASD was sparked by the Pre-Kindergarten teacher and her knowledge of ASD which greatly helped this family begin the journey to diagnosis. This participant used this information from the teacher and started seeking answers. A teacher, doctor, or family friend were the three individuals that alerted participants that their child exhibited ASD characteristics if the participants were alerted at all.

One parent, Raksha, was informed by her son's doctor for the need to have him evaluated for ASD. Upon hearing the term ASD, and that her son needed an evaluation, the participant felt a rush of emotion initially but found herself doing research:

But it was kinda like I froze during that moment and just kinda my mind went a

> thousand places and I, I couldn't come up with any questions. And then I think, once I got home and got him settled, I just remember like now I'm doing all this research trying to figure out what is this and why does she want to evaluate him for that

Other participants share the feeling of shock or denial when being told that their child needed to be tested for ASD mainly because they were unaware of what this meant. Researching ASD, interventions, and participants discussed providers as an essential step in their journey to obtaining an ASD diagnosis for their child.

The need to research ASD and acquire knowledge specific to the child grew amongst the participants after obtaining the diagnosis. For example, Ophelia described her immediate thoughts upon hearing that her son was diagnosed with ASD:

> When the psychologist told me, I was like okay, so what do I need to do now? I wasn't devastated because like I said with everything else that was going on in my life, I was like, I just want him to have the assistance he needs

Her next thought was to get help for her son and to seek advice from the psychologist immediately. Once being told that their child could have ASD, the participants all requested medical and professional assistance to begin the process. However, some participants had a long wait to have their child meet with a developmental pediatrician or child psychologist. This wait was due to different factors that were based on Medicaid requirements or a limited number of clinicians able to diagnose ASD in the area. Tara shared her experience once she knew her son was struggling and that it could be ASD, but she was waiting to see the developmental pediatrician:

> I was just waiting and waiting, and almost two years I guess. Or a year and a half.

> And when his behavior started showing and the teachers started telling well he's doing this and he won't sit down, he's running. I didn't know what was going on and like I said, led to me doing research on autism, I was like okay, let's just get him to his doctor and find out if she can help

This parent did not let the long wait deter her from seeking help for her son in any way she could which led her to get involved with his school as a volunteer and learn more about ASD as they waited for the diagnosis. The need to do whatever needs to be done for the best interest of the child was a strong sentiment expressed by the participants.

Theme: "I chose him"

One semi-structured interview question asked the participants are there any ways that [CHILD's] diagnosis has impacted your family? Carr & Lord (2013) found that African American mothers perceived less negative impact on their well-being and expressed less social, emotional, and physical burdens than their Caucasian counterparts. This question sought to gain insight into the impact on the families in this sample to determine if the perceived impact was similar to the findings in Carr & Lord (2013). The responses to this question gave insight into the specific struggles that the participants in this study faced and 8 of the 12 interviews revealed how having a child with ASD impacts them socially and financially. However, the participants decided to put their child first regardless of the sacrifice necessary. The theme "I chose him" produced the finding that the participants were so dedicated to providing care for the child that any obstacles that presented themselves were managed with the child as the priority.

For instance, Darrielle shared how she delayed her career and school goals

because her son needed her time and focus as he acclimated to school. She felt pressure to drop everything and pick her son up whenever the school called which led to her making a major decision:

> When the school kept calling, kept calling I had to stop working. I was like well it's either work or my baby suffers and being that I chose him over work, I get blamed by my family and asked when are you going to go back to work

It took time for her son to settle into the new school environment and get the necessary supports to help him feel successful. During the interview, Darrielle shared that she thought that her son had made enough progress that she could begin to look for work again but that she had to choose him over everything. She gave him her attention when he needed it most, and she feels that this was a significant factor in his progress to this point.

Having to make decisions about your career centering on the needs of your child was a common theme in the interviews regardless of the parent's income level. For instance, Raksha discussed her choice to continue to teach online to give herself the flexibility necessary to attend to her son:

> I've just spent a whole lot of time in doctor's offices and a lot of time, um, being on guard. So I never know when I'm going to get that phone call, go pick up your child. I'll pick up my child, you know. Um, it's probably changed me a little bit in terms of my work because I work from home and I teach online, which I love, but I think I'm also a little hesitant to get any kind of job that's going to be boxed in where it will be harder to get away if I need to, to attend to him

Her son's needs take priority in decision making because she knows from past experiences that the school calls for her son to be picked up because of his behavior. Several participants shared similar experiences of having to go pick their child up from

school based on behavior instead of the school staff possessing the tools needed to de-escalate the situation. The inability of school staff to remediate the child's behaviors prevented Carol from keeping her job, "I'll just come get him and find out what's going on and believe me it happened a lot. The jobs just don't understand that nowadays. I'm like okay now I got to pick him over the job." The school's response to behavior directly impacted the careers of some participants because flexible jobs are essential but are not always the best paying jobs.

The majority of the participants did not complete a college degree which is important to note because this decision was often made to be able to best support their child. For example, Brittany shared that she needed to stop pursuing her education to manage her child's needs better "I do have one degree in business, and I was going for my bachelors actually when I got pregnant with him. And I had to stop because of everything that was going on." She is now able to consider focusing on her education again because her son's behaviors have improved and so has her health. Juggling the needs of a child with special needs and her health concerns as a single parent made everything too much to manage which is why she decided to make her son a priority.

Financial struggles for participants were commonly discussed, but the sacrifice was deemed necessary because the parents believed strongly in choosing the child first. Caitlin shared that her twin sons with ASD were abused at a previous daycare which led her and her husband to seek alternatives that ended up being more expensive. Maintaining her sons' safety and well-being was worth the financial sacrifice:

> Daycares are really expensive. We actually found one that's supposed to be for kids with special needs and basically understanding to the child's needs. It's expensive.

> Those are the two main things. Basically, I just do what I can. Financially, just to make things work. Penny-pinch

Regardless of the sacrifice, the importance of meeting their child's unique needs is paramount to the participants. Participants shared feeling overwhelmed at times with having to find ways to accommodate the child and to finance services. In spite of this stress, Janet shared a sentiment shared by several participants, "I was never scared or anything because I'm supposed to take care of you, so I guess I got to do what I got to do." The financial and social barriers were present but not a hindrance to the point that participants were deterred and instead they each chose to put their child first.

Theme: "It's mind-boggling for the Black community"

Some of the overwhelming feelings felt by the participants were related to being the sole caretaker of the child and lacking the support from family. Five participants discussed how ASD is rarely discussed in their families and communities, the importance of ASD awareness, and even offered suggestions on how to better support African American families. The parents in this study shared that in the African American community there is a universal mistrust of doctors and of the healthcare system which can impact how parents seek help. This relates to the findings from Burkett et al. (2017) in which African American parents sought respect from health care providers to recognize and acknowledge that African American parents hold values and beliefs from childhood. African American parents in Burkett et al. (2017) described a need for respect regarding their parenting abilities and withholding judgement of diverse cultural views on the upbringing of children. These cultural views impact how parents interact with their

children and also impact the collaboration with health care providers that are unaware. The theme "It's mind-boggling for the Black community" presented the following finding the cultural background of the participants influenced how they were able to successfully obtain an ASD diagnosis for their child and as a result the African American cultural experience needs to be accounted for throughout the process.

Parents in this study also discussed how the African American culture impacts this struggle and that doctors are often unaware of these cultural norms, "We handle things a little differently than a Caucasian family sometimes. We have different cultural beliefs and stuff like that. It's definitely shocking to us." This shock was often described as disbelief or denial because the parents felt they knew so little about ASD and how their child would be diagnosed with ASD. Parents shared that the initial shock was from trying to understand it as a parent they could have prevented the child from having ASD. Several participants explained their initial struggles with blaming themselves for giving their child ASD and how difficult it was to move past this feeling. Knowing family members with ASD and not paying attention to the signs their child exhibited or using recreational drugs during pregnancy were two examples of participants blaming themselves. This blame was very deep for some and even painful to discuss during the interview years after receiving the diagnosis.

Blame due to misunderstandings related to ASD and its causes further complicated the diagnosis process for some participants. Understanding the complexities of how African Americans can feel uncomfortable seeking help from clinicians, participants offered suggestions on how clinicians can help families. For instance, when

telling a parent that their child has ASD understand that parents may initially feel overwhelmed like Xavier, ”maybe even though I didn't have questions, maybe tell me some stuff anyway because I think I was in the state of shock.” Several participants recalled being given documents upon hearing of the child’s diagnosis but not knowing what the next step should be. At the moment when a parent heard the diagnosis, several emotions were arising at the same time which made it difficult to decipher the amount of information presented. Parents shared that a follow-up phone call or meeting with the clinician would be helpful once a parent has time to grasp the ASD diagnosis.

If a clinician notices a child is not meeting developmental milestones a pressing recommendation from participants was for clinicians to inform parents of the importance of these milestones and the options for delving deeper to determine if the child has additional needs. Some participants felt that clinicians need more information on how to interact with African American families and families need clinicians to take charge of the appointments and coach parents through the process. Kerfeld, Hoffman, Ciol, & Kartin, (2011) discussed benefits when providers acknowledge the diverse care provided by African American families, and offer health care and social supports by realizing the various social structures of African American parents caring for their child with ASD. Kerfeld et al. (2011) found that these providers can give culturally congruent care and decrease ethnocentric views that interfere with the quality of care. Providers supporting African American parents through culturally congruent care is necessary because parents in the sample reported being less knowledgeable of the signs of ASD and a reliance on the provider’s expertise. In this study, Darrielle shared that the road to diagnosis took

longer because she was unaware of the signs of ASD, “I think they need to let us know right away. Look let's have him tested for such and such just to see. I think that would help us African Americans a lot because some of us don’t know.” She now understands the impact that early intervention had on her child and felt that many African American parents may miss out on these benefits the longer they wait for the diagnosis. The desire to have known sooner so the child could begin interventions faster was a prevailing sentiment among participants.

Participants felt that the testing or intervention options need to be offered and explained to families once symptoms arise. Raksha had a positive experience with her son’s clinician reflected on how other clinicians can help parents:

> Maybe they can be a little bit more inviting or definitely pass on more information to families so that may be more welcoming, basically, so that they want to get their child help or get their child tested or just to know that their options are available and there's help available basically

Educating other parents has been a mission that many of the parents in this sample have taken on personally because they did not feel the clinician was welcoming or explained the options thoroughly. Two parents have ambitions towards developing an outlet whether it be a blog or non-profit organization for parents to get the information on ASD that they felt they missed. Providing the necessary information on ASD diagnosis and what resources are available are paramount to helping parents get the best care for the child, and most parents in this sample felt they needed more.

The participants in this study also struggled with understanding how to best support their children by asking for help. Tara shared that African American parents

think they can fix whatever their child is struggling with, "I think a lot of our people they get scared to get help for our kids. They think that they can nip it in the bud." This notion of "nip it in the bud" or being able to fix the problem yourself and quickly is not the best approach to take when supporting a child with ASD which parents shared that they later realized. However, participants discussed that this initial culturally driven approach to handle a situation at home could hinder parents and complicate the struggle to understand ASD and how it affects your child.

EXPLANATIONS FROM THE SAMPLE

The second research question that this study focused on was, in what ways do these experiences help to explain factors that affect ASD diagnosis for African American children? The diagnosis disparities that impact ASD for African Americans include misdiagnosis, late diagnosis, and improper diagnosis. To answer this question, the parent needs assessment that was completed by the participants was analyzed along with the archival data and interviews. The archival data were copies of the ASD evaluations provided by the participants from schools, therapy centers, or doctors. The ways that the experiences of participants help to explain diagnosis disparities are the impact of evaluations, impact of access to healthcare, and the impact of the parent. The explanations gathered from dissecting these data are specifically related to the participants from the sample because of the small sample size restricting the inability to generalize and provide broader explanations for African American parents.

The impact of evaluations

Mandell et al. (2009) found that White children were more likely to receive an ASD diagnosis than their African American and Latino peers. African American, Latino, and Asian children in this study that met the criteria for an ASD diagnosis were un-identified and instead categorized as a child with a 70 IQ or lower. Jarquin et al. (2011) found that African American children were 50% more likely to meet ASD eligibility criteria and not have a documented ASD diagnosis than their White peers. Of the children in this sample, 9 of the 12 had another diagnosis before obtaining the diagnosis of ASD. Responses from the parent needs assessment show that the children were diagnosed with developmental delays (3), intellectual disability (3), learning disability (1), and ADHD (2) before receiving an ASD diagnosis. Both of these studies relate to the findings because the nine children with a previous diagnosis were delayed access to ASD focused interventions when the children did have ASD. The prior diagnoses highlight the need for accurate evaluations which the parents in this sample eventually obtained. An accurate assessment is comprehensive and evaluates the child in different settings, using multiple assessments, includes input from parents, and analyzes all data collected.

The archival data received from the participants displayed examples of accurate assessments with the components necessary to support the child holistically. However, Courtney shared that on the journey to obtaining an ASD diagnosis she had to have her son evaluated upon moving to a new state. The test results came back to show that her son did not have ASD which was a shock to the parent because he had a previous ASD diagnosis. This experience offers a unique insight into how the evaluation process can

lead to an inadequate assessment of a child resulting in an alternate diagnosis. Courtney shared how she felt after hearing that her son had ADHD instead of ASD:

> When I read it, I was very disappointed because it was not a thorough evaluation like what I experienced in Georgia. And so for her to come back and say like, hey, you know, all I see is ADHD symptoms and um, he might be gifted, and that was it. And you didn't really review any kind of records. What's so crazy about the ADOS is just a snapshot. So whenever you give it, you're only with the kid for that small amount of time, that's why you're supposed to do other things. You're supposed to get info from the parents and the teachers and review records. It's not a standalone test

Courtney's experience shows how essential it is to have a full evaluation done that reviews information from multiple sources and analyzes the child using different assessment. This evaluator did not request her son's previous evaluation nor did she collect any interview data from the parent. Without the necessary data, the evaluator made a decision on the child's needs that did not support the previous evaluation or those subsequently conducted.

Angell & Solomon (2014) found that the developmental history and contributions of the parents varied and were either ratified or negated by the evaluator. After reviewing the archival data submitted by participants in this study, these evaluations found ways to discuss the critical aspects of the child's medical history and ratified the parent's input. For example, an assessment completed by a school district shared the reason for referral and provided an overview of the reviewed information including parent input about the child's behavior. Another report provided by a private Autism Center discussed the family, medical, and developmental history that included aspects from a parent interview form. An evaluation done at a university's Autism Center provided direct quotes from

the parent about the child's strengths and weaknesses. The evaluation serves as a tool to inform clinicians, teachers, and parents about the child's needs and to offer recommendations. However, without an accurate assessment, it hinders the parent from taking the necessary steps to support the child.

The ASD evaluations of the participants' children were analyzed for the presence of any discriminatory verbiage about the parents or child. Findings from Angell and Soloman (2014) showed that African American parents' concerns are often omitted from the ASD evaluation and that the language used to describe the families can be different than the language used to describe White families. The evaluations provided by the participants came from developmental pediatricians, school districts, privately run and university funded ASD centers, and from psychologists. These evaluations did not contain any language describing the parents nor the child that would present them negatively. There were twenty-five children in the ethnographic study conducted by Angell and Solomon (2014), and this study had twelve participants. The smaller sample size may be a reason behind the absence of a similar finding however it is preferred that African American families are not discussed in a contrary manner; therefore, this finding is promising.

The impact of access to healthcare

Emerson et al. (2016) found that a primary care physician diagnosed 18.7% of White children and 36.8% of African American children. Of the participants in Heejo et al. (2016) 18.7 % of White children and 36.8 % of African American children were diagnosed by a PCP. These studies are examples that highlight the difference in the role

of the primary care physician for a White child and an African American child. African American children are more likely to be identified with ASD by their primary care physician making the physician's ability to recognize the signs for ASD a crucial aspect in diagnosis.

When participants in this study were asked in the interview to share anything that they felt that clinicians needed to know, the interaction with physicians was a part of the discussion. Tara shared the experience with her son's pediatrician that did not agree with her assessment of her son's lack of progress:

> Well definitely for the doctor who missed it. I think having the humbleness to refer over. So, you know, I think with him it would've been nice if he says, "you know what I'm not seeing it, but you know because there's something here. Let's refer to a developmental pediatrician

The pediatrician is often the first individual to hear about the child displaying ASD characteristics, especially for African American children. Obtaining a referral to a developmental pediatrician to determine if the child needs further evaluation could have been the next step for this family, however, the parent sought an outside agency to evaluate her son.

The parent needs assessment revealed that the children were evaluated by the educational IEP team (5), a developmental pediatrician (4), or by a psychologist (3). The evaluator chosen serves importance in the timeliness of receiving the diagnosis because if a referral is necessary, then this can slow down the process depending on how many office visits it takes to get the diagnosis. For instance, Mandell et al. (2002) found that 72% of the White children received an ASD diagnosis upon the first mental health visit

however 57% of the African American children received an ASD diagnosis on the first visit. Mandell et al. (2007) found that 34.7% of Black children were diagnosed with ASD on the 1st visit compared to 60.2% of White children. The more appointments it takes to receive a diagnosis lengthens the amount of time before a child has access to the appropriate interventions.

In this study, Raksha shared the importance of receiving interventions early and the doctor's role in facilitating this strategy. When asked to share her opinion on what clinicians need to know this parent mentioned a suggestion:

> It probably needs to be on their continuing ed list more because it seems like it's much more pervasive and you're probably seeing people in your office earlier and earlier, and the sooner you pick it up, you know, the sooner you can get intervention services so you probably can make a difference

With new research emerging on a reasonably consistent basis, disparities the recommendation to have doctors participate in continuing medical education focused on ASD is a logical one considering the role that doctors play in the journey to diagnosis. Often multiple doctors interact with the family during the diagnosis process according to the parent needs assessment. Six parents met with two professionals professional before receiving the diagnosis; five parents met with only one professional, and one participant met with three professionals. Participants also reported the distance they traveled to meet with professionals while on the journey to obtaining a diagnosis. Seven participants drove 0-20 miles, four drove 21-40 miles, and one drove 41-60 miles. Participants invested varying amounts of time to travel for multiple office visits which solidify the need for better physician and patient interaction because of the importance of the

physician's role and the time that these families spent.

A factor that impacts the number of doctors visits and the distance driven to access a provider is the type of health insurance that the family has. Seven parents had Medicaid, and five had private health insurance. Two families used grants for children with ASD to pay for services, and of these two, one participant also used Medicaid and the other private health insurance. It is important to note that the participants struggled on the road to diagnosis regardless of the type of health insurance they used. Participants with Medicaid and with private insurance both encountered their child being misdiagnosed. The hierarchy set in place by the insurance provider impacts what professionals are available to their child, but there were no apparent differences in the obstacles for parents based on using private or public health insurance.

The impact of the parent

Christensen et al. (2016) found by analyzing the Autism and Developmental Disabilities Monitoring (ADDM) Network that the average child in America is diagnosed with an ASD by age 46 months. Of the twelve participants, nine received an ASD diagnosis for their child before age 4. The parents in this study provided insight into how African American parents obtain a diagnosis of ASD for their child promptly. The participants in the sample were asked in the parent needs assessment to share the age at which they were first concerned for their child's development. Seven participants noticed concerns at age 1; four noticed concerns at age 2 and one noticed concerns at age 3. The participants were not initially aware of the characteristics of ASD, but they saw early on in their child's development that there was a concern and opted to pursue the

answers they needed.

The participants in this sample live in different states, have various levels of income and education, yet they share a commonality, the drive to support their child at any cost. These individuals often shared experiences that provided a glimpse into how they help their child with such fervor and relentlessness. When asked to discuss her hopes for her sons' futures Caitlin discussed the importance of pushing them to show them their capabilities:

> Right now, I'm just whatever I can do to get them help. Any therapy, things I do with them at home, activities. I make sure it's geared to what they're teaching them in OT, speech, ABA, what they're doing. I implement everything. I just push it. I just push it to the limit with them so that eventually they'll be able to hopefully just function and not have that stigma that they can't. That's my main goal

This parent's perception of her sons shaped her interactions with them and drove her to get them into a better daycare and provide access to the necessary related services. Her stance on implementing the recommendations of the providers and fully supporting the progress of her sons was a prevailing sentiment shared by the participants.

Another unifying trait present is the resilience of the participants. One interview question asked the participants how they overcome the impact of ASD in their family. Carol was invited to share her suggestions for what doctors could do to make the diagnosis process better for African American parents. In her response, she shared the tenacity that parents related to by being the provider for the child and doing whatever it takes to support the child:

> I just wish the doctors wouldn't be so judgmental from the professional standpoint, versus look at it from, if you really was that parent, who had to live through that, and had to go through that, from diagnosis to having to deal with people making

> fun of your child all the time, and having to always be their voice, even though you're tired. I'm so tired, but I fight all the time, because I know if I don't, he can't

Carol's comment gives a glimpse into the internal struggle she was enduring to fight for her son because of the obstacles encountered with her son's pediatrician. The pediatrician was from a different culture than the family, and this participant felt disregarded by the pediatrician especially when attempting to discuss her son's development. Despite the opposition, this participant took the responsibility of being her son's voice as her primary mission and weathered storms that came forward as a result of this mission.

Ten participants in this sample discussed religion as their primary support system when enduring difficult times. This method of handling life's obstacles is what Koenig, Pargament, & Nielson (1998) referred to as religious coping which is the use of religious beliefs to facilitate problem-solving to prevent or alleviate the negative emotional consequences of stressful life circumstances. Parents in this study, discussed how their faith sustains them and how they rely on God as their ultimate support system. Teresa discussed how prayer helps her overcome when obstacles present themselves, "I have to go on my knees and pray to God or I go to church and mediate because nothing else will do." Xavier shared how faith not only helps him get through tough times, but it also helps him look to the future for his son:

> I'm a Christian, and my faith has gotten me through life, so it just gets stronger and stronger. Every time a crisis comes, that's when I run to God, and He has never failed me. So, um, it also saves my perspective. So it kind of helps me to try to look beyond the autism diagnosis and also look at the gifts that are just getting acted out through the diagnosis because he's trying to fit into this world

His viewpoint of focusing on the gifts despite struggles his family endures also emphasizes the view of the participants. The participants each shared their hopes for their child's future and their favorite memories to date with their child. At this point in the interviews, after discussing the tense topic of the journey to diagnosis, each parent seemed uplifted when talking about their happiest moments to date. Raksha shared how her son loves to watch football, "He'll sit there with his dad, and scream at the TV, and he'll mimic the plays." Caitlin discussed how emotional she gets when her son's communicate with her:

> Them communicating with me and talking have been definitely highlights. Every time they do it, I just tear up because when you're not used to something and you see all those parents talking and their kids saying stuff. You just don't realize what you have until you don't.

Obtaining an ASD diagnosis for their child has been difficult for each family in different ways, but the joy that their child brings was the most prevalent sentiment shared by all.

Chapter 5: Discussion

With differences in diagnosis rates, timelines and the presence of disparities in awareness, knowledge, and receipt of services, African American parents face challenges to securing a diagnosis and obtaining effective treatment for their child. The delay of diagnosis postpones created a targeted plan of action for the child which ultimately, impacts the child's access to ASD specific interventions. However, there is a gap in the research regarding how parents can obtain an ASD diagnosis. The purpose of this study was to present findings that speak to the ASD diagnosis experience for a sample of African American parents. Receiving an accurate and timely diagnosis for a child is the primary hurdle many parents face and this study sought to understand why by learning from parents that have navigated the process.

THE PARENT AND PHYSICIAN PARTNERSHIP

Physicians play a more significant role in the diagnosis for African American children with an ASD, but it takes more visits to the doctor's office to receive an ASD diagnosis for an African American child. This racial disparity for ASD diagnosis does not have a clear explanation; however, there is an experience from the participants that may provide insight. One participant shared her concerns about her son's development, but the physician did not address them. This participant later researched the behaviors her son was exhibiting, but her experience displays a discrepancy that should have been a call to action. African Americans and Whites may be treated differently by physicians when first reporting ASD symptoms due to clinicians' expectations about treatment and service needs by race. These predetermined understandings further complicate the

diagnosis process for African American children with ASD and delaying this call to action.

African American parents deserve to have their concerns heard by the physician because race should not be a factor in care based on a disability or need. However, DisCrit theory claims that race does not exist outside of ability and ability does not exist outside of race; each is built upon the perception of the other (Crenshaw, 1993). This distorted relationship between race and disability leads to bias, particularly with physicians. For instance, African American parents in Gourdine, Baffour, and Teasley (2011) reported the clinician perceived them as uneducated, seemed to have a cavalier attitude about the expectations of the child and they felt clinicians were pressuring them to agree with their methods of treatment or assessing the child. In Burkett et al. (2015), healthcare professionals noted the potential for a professional bias toward the diagnosis of the White child with ASD because this group is diagnosed most often. Healthcare professionals may not be screening for ASD in African American children as quickly as they do for White families because of predetermined understandings of how to assess parent concerns based on race.

Diagnostic delays may also reflect differences in parental initiation of diagnosis, which could be influenced by the likelihood that African American parents do not feel like partners in their child's healthcare process. In the African American community, mistrust of the medical establishment is validated through a longstanding history that still resonates today (Poussaint & Alexander, 2001). When a parent's concerns are not addressed their reality as a parent to a child with struggles is discounted.

DisCrit theory urges individuals to recognize the intersectionality of race and disability, the impact it has, and the need to address multiple grounds of identity when moving forward (Crenshaw, 1993). The beliefs of the parent and the physician should be equally valuable, and the diagnosis process should be a collaborative effort. The influence of race on disability and vice versa is complicated for both parties involved to understand that is why the partnership is essential initially. These negative interactions with healthcare providers can influence the parents' willingness to seek medical advice and care for their child, including their decision to seek referral appointments with specialists.

This collaboration will not remove the burden on healthcare providers to end clinician bias based on race. Seven of the twelve participants in this study were referred to another professional before obtaining the ASD diagnosis. Less frequent referrals to the necessary health care professionals could influence delayed diagnosis and delays in treatment, both of which can be detrimental to the patient. With the diagnostician type differing by race, this puts more pressure on physicians to resolve issues related to diagnostic timing because these factors impact African American children at a higher rate. An issue affecting diagnostic timing could be the physician's knowledge of the presentation and treatment of ASD and how this influences the ability to diagnose patients adequately. To provide more competent care, there must be an improvement in patient-centered communication to strengthen the parent and physician relationship. The medical community needs to address these differences to provide culturally relevant care to African American families; however, there is a lack of research regarding the African American parent's experience with ASD. There is a unique and valuable cultural

experience that African American families bring to the diagnosis of ASD and more research is needed to fully take advantage of this knowledge.

Reciprocity

Maximizing the impact of African American parents in the essential role that they serve, the caretaker, is a crucial part of establishing cultural reciprocity between physicians and patients. Kalyanpur & Harry (1997) introduced cultural reciprocity as the development of a collaborative relationship between the parent and practitioner that exposes and conquers underlying assumptions the practitioner possesses about disability and culture. The purpose of cultural reciprocity is to highlight the perspective of parents that tend to be disenfranchised and marginalized within the special education system. The focus on this perspective leads to opportunities for professionals to encourage families to participate in a collaborative effort to support the child.

The burden is on physicians, evaluators, and diagnosticians to not abuse the power they have due to experience in the diagnosis process and their understanding of procedures. Instead of focusing on the power the professionals have based on expertise, the focus of the IEP process should shift to focus on the power the parents hold. By openly working with families, physicians can gain valuable insight into the culturally influenced behavior scripts that parents instill in their children. These scripts are evident in each culture; however, most are unaware that their behavior is deeply rooted in culture and blindness to this fact can adversely affect interactions.

Cultural blindness plays an integral role in the continuation of cultural misunderstandings that negatively impact the identification of culturally and

linguistically diverse students with disabilities. By embracing cultural reciprocity, collaborating with families and focusing on understanding the needs of students from a cultural lens, then culturally and linguistically diverse students and their families can receive support that is both accurate and culturally relevant. To stop cultural blindness and the impact it has on the assessment and identification of African American children with ASD, this dialogue between families and service providers is essential. Participants fought for their children in different ways and fostering cultural reciprocity could make the fight less strenuous for families.

Taking time to learn from parents, is the focus of the culture of reciprocity and by operating under this mindset, practitioners can foster a collaborative relationship with African American families. By encouraging practitioners to evaluate their own biases and collaborate with the families during the assessment process, misconceived notions regarding the interactions with African American parents could be understood within a cultural context. To focus on the families' voice Kalyanpur et al. (2000) discussed an argument from Serpell (1994), "negotiating a fusion of horizons to seek a common ground between the explicit formal constructs and theories of educational establishment and the implicit ethno theories in the children's homes." This fusion of horizons serves as a means to discover the compromise between parents and diagnosticians. Finding the middle ground requires viewing interacting with families through the understanding of cultural reciprocity.

Culture

The participants in this study utilized their cultural capital while obtaining the

ASD diagnosis for their child. The basic premise of the cultural capital theory is that people acquire and use information and knowledge (i.e., cultural capital) and social networks (i.e., social capital) similar to how they use economic capital (Bourdieu, 1974). More specifically, cultural capital refers to information and dispositional knowledge that informs our beliefs and actions.

The participants in this study were able to have successes by utilizing their cultural capital. Teresa shared the discussion she had with her mother after first learning of her son's ASD diagnosis. At this time she had mixed emotions of shock and worry, but her mother cautioned her that ASD can't be cured but also pushed her to seek answers for her son. Her mother's guidance and support during this time were used to tap into social capital by using connections in her mother's network to acquire access to therapies and interventions. This access varied for participants based on family structure, and support systems present however regardless of variations the participants were able to utilize cultural capital on different levels.

Another cultural factor evident in the participants' experiences from this study during the ASD diagnosis process is the way the parents view their child's needs. Some African American parents view their child's difficulties differently based on cultural beliefs. Participants in this study were asked during the interview to share some of their best moments to date with their child, and the responses displayed the pride the parents felt for their child and the joy that the child brings to their lives. The participants shared how their child makes them laugh and spreads joy to other family members by just being themselves. Their child with ASD was viewed as a unique member of the family with

fun interests or even the ability to bring levity to situations instead of regarded as a difficult child. The perceptions of the participants in this study highlight the finding that the parent's cultural heritage serves as a lens to interpret their child's disability.

Another lens that shaped the participants' perception of their child's disability was religion or faith. The church has maintained cultural influence in the African American community for hundreds of years as a symbol of refuge. Historically, the church has assisted African Americans throughout the struggles for integration, educational access, economic quality, and social justice (McCray, Grant, & Beachum, 2010). Nine participants in this study referred to their faith and religion as the factor that helps them overcome. This belief is common in the African American community because the church is heralded for providing an uplift in times of crisis. Carol shared how prayer gives her solace during tumultuous times and her relationship with God sustains her. Carol is a grandmother that ended her in-home daycare business to have the flexibility to support her grandson that she has custody over. Her life changed drastically when she accepted the role as caretaker of her daughter's children, but her reliance on her faith provided her the support she needed. Other participants shared how daily prayer, meditation, involvement in their church, and their belief that God will make everything alright uplifted them in times of struggle.

African American families are less often to be included in ASD research. Research-based, parent-implemented interventions reflect the values, preferences, and results of families included in this research base leading to less effective strategies to support African American parents with a child with ASD. This study highlighted the

voices of twelve parents to bring insight to the literature regarding the experiences of African American parents. These experiences unearthed critical reflections regarding the impact of race in the ASD diagnosis process for parents in this sample. The theme "It's mind-boggling for the Black community" provided some insight into how African American families need more from the ASD diagnosis process. Participants suggested ways that health care providers can better support African American families such as giving them the information necessary to make informed decisions or not relying on the parents to divulge concerns and to ask specific questions to obtain a holistic view of the child.

There was an experience from a participant that was not frequent enough to present a theme however, these experiences were based on race and culture and present valuable insight to the diagnosis experience for these participants. For instance, Tara's concerns with her son's development began near age 1 however her doctor was unresponsive to these concerns. Tara shared how difficult it was to get the pediatrician's support, "with my doctor, and her not being compliant, because, like I said, she's Asian, and it's always a difference with other races who you're working with." Tara discussed how she proceeded to get a second opinion due to the lack of cooperation from her doctor which she felt was due to the racial difference between the pediatrician and her family.

The desire for a partnership with the health care provider is evident amongst interviews with parents. The ability to collaborate effectively with a health care professional should not be influenced by the race or cultural background of the parent however previous studies and a participant in this study present a harsh reality that

counteracts this viewpoint. Rojas, Walker- Descartes, & Laraque- Arena (2016) did a literature review to determine the presence of implicit and explicit bias toward African Americans within the health care system. Rojas et al. (2016) found that in 26 studies it was evident that most health care providers have some level of pro-White/anti-Black bias ranging from slight to strong bias. Rojas et al. (2016) also found that African American patients rated their providers lowest on measures of warmth, friendliness and satisfaction when interacting with physicians.

Tara's interaction with her child's pediatrician, the findings from Magaña et al. (2015) and Rojas et al. (2016) highlight how African American parents can be treated differently in the healthcare system. This racial difference could be based on bias on the behalf of the provider however, regardless of the cause of the difference in treatment, African American families need a fair opportunity to have meaningful collaboration with their healthcare provider. The hindrance of this collaboration negatively affects the ASD diagnosis process for parents like Tara and delays diagnosis for children like her son making the need to decipher this issue paramount.

FUTURE RESEARCH

Diagnosis can be delayed for African Americans with an ASD, and these children are more likely than their White peers to be diagnosed by a primary care physician. This finding from the literature leads to further questions regarding the adequacy of training that physicians receive in treating children with ASD, the amount of exposure to children with an ASD, and the time physicians can devote to patients. Furthermore, based on the responses from the participants in this study, more research is needed to determine if

clinicians have different expectations about treatment and service needs based on race. The perceived impact of an ASD diagnosis on the patient may also be a factor for the delay in screening and diagnosis making this an additional question for future research. The participants reported feeling overwhelmed or shocked but some felt relief after finally getting an answer to explain their child's behavior. Research on the impact of an ASD diagnosis is necessary to understand better how practitioners should relay this information to families.

An additional area for further research in the field of parent's healthcare perceptions. More research is needed to understand why African American parents self-refer their child at a different rate. Perhaps parent perceptions regarding discrimination in the healthcare system are rooted in the parent's personal healthcare experiences. One parent shared her negative experience with her son's primary care doctor that she believed were rooted in the fact that the doctor did not share her cultural background and therefore could not understand it. These perceptions may be impacting the underutilization of medical care and may also lead to delays in medical tests and treatments. Future research could focus on these questions as an attempt to determine whether African Americans' perceptions of the healthcare system can be altered and if so, how.

Further research is also needed to determine how familiar parents are with evidence-based interventions because once a child receives an ASD diagnosis, the partnership between the parent and clinician must then focus on intervention. Participants were aware of their child's need for occupational therapy and speech therapy

for example but are African American parents aware of these options and there importance. Parents should participate as partners in the therapy process: however, their access to knowledge about interventions would be essential to research to understand how parents engage in this partnership with clinicians.

LIMITATIONS

Limitations of this study include the sample size, completing interviews via phone, and the variation in African American culture. To reach participants across the country, it was necessary to conduct interviews by phone instead of in person. The ability to build rapport with a participant by telephone can present a challenge. Using phone interviews was not the preferred method of collecting interview data however, the participants did not all have access to devices that could be used to video chat. The participants involved in this study shared experiences that were personal and sometimes painful and being able to interview them in person or virtually would have provided a deeper level of understanding. However, the participants gave so profoundly of themselves and opened up throughout the process regardless of interacting with the researcher by phone and emails leading to rich data that supported this study.

Different groups comprise the African American populations, and in this study, the only criteria to be considered based on race and ethnicity was if the participant self-identified as African American. It is also important to note that the majority of the participants were from southern states where cultural values may differ from those that are more urban. The experiences of one small subgroup may not generalize to African Americans in other regions of the United States. Two families also identified as have

Latino heritage and one family was from the Caribbean. These participants may or may not share similarities in customs, class, spirituality, values, experiences, and sociocultural identification. Therefore, due to variation, it is difficult to generalize to all African American parents with a child with ASD.

Another limitation that impacts generalization is the sample size because there were 12 interviews conducted. The information gathered from the participants provided valuable insight into the experiences of these parents throughout their journey to obtaining an ASD diagnosis for their child. There are very few studies that address diagnosis disparities in ASD from a qualitative methodology which makes this study and others like it essential. Despite these limitations, this study brings new findings in a sample of families that have been traditionally underserved in the ASD literature. The perspectives represented in this study are those rarely sought out in the research community; therefore, the hope is that this study will lead to further research utilizing parents from culturally and linguistically diverse backgrounds.

IMPLICATIONS

Healthcare professionals in Burkett et al. (2015) believed that it was more difficult for African American families with a child with ASD to access resources due to limited economic resources, knowledge gaps regarding ASD and the utilization of different social networks than their White counterparts. The different capacity for all parents to attain as ASD diagnosis for their child drives the need for accessible information. Implications for healthcare professionals include providing this access to parents by sharing knowledge and helping parents connect with the proper resources.

The expectation that African American parents will know the right questions to ask to facilitate the ASD diagnosis should be replaced with the expectation that parents need this information if their child is exhibiting characteristics of ASD even if the parents do not ask. Participants recommended that healthcare professionals give parents the options for testing and interventions when a concern arises so that parents can make the appropriate decisions for their child. Without the information and resources, healthcare professionals should not expect parents to understand the options; therefore, the responsibility of these explanations resides with providers.

Healthcare providers should also listen to the concerns of African American parents and refer to a specialist if the provider is unsure how to proceed. Several participants had their concerns disregarded, and the physicians even convinced some participants that their child was developing slower. Utilizing cultural reciprocity in the parent and physician partnership can lead to meaningful collaboration between both parties in the best interest of the child. Parents play an integral role in the life of their child and should be valued as worthy partners in healthcare decisions. African American parents want to be heard, want to feel like there is a partnership with their child's healthcare providers, and want to be provided the necessary information to make the best decisions for their child.

The parents in this sample made decisions for their child that lead to an accurate and timely ASD diagnosis, and their experiences offer implications for other African American parents. Parents should not be expected to become ASD experts and know every characteristic of ASD however when their child exhibits any behavior that seems

out of the ordinary parents needs to alert the healthcare providers. Assessing the situation by reporting atypical behaviors can lead to determining the need for further testing or interventions to help the child regardless if ASD is the cause of the behaviors or not. Acquiring the necessary services to support the child only becomes attainable if healthcare providers are aware of a need and take action. Some participants felt that something's not right but did not report these suspicions to a healthcare professional. Parents should share this information with providers even if they are unsure because early intervention is crucial and the wait to report this info can be a hindrance.

Another implication for African American parents is to hold fast to those inclinations if something's not right. Participants were tenacious and pursued the resources necessary to support their child at extraordinary costs while obtaining an ASD diagnosis because the child was the priority. Find ways to research providers, interventions, and services for the child to acquire as much knowledge about ASD and the systems and organizational structures that monitor this information and resources. With this knowledge, parents can be effective partners that are actively involved in the diagnosis process and are unmoved by obstacles presented during the process.

CONCLUSION

This study sought to answer the following research questions: how do African American parents describe their experiences related to obtaining a diagnosis for their child with an ASD and in what ways do these experiences help to explain factors that affect ASD diagnosis for African American children. The themes that connected the experiences from the participants were the conviction that there was something not right,

the drive to learn more about ASD, the desire to put the child first, and an understanding of how understanding ASD is difficult for the African American community. Through analyzing the experiences of a sample of African American parents with a child with ASD, the data provided readers access into the journey from the vantage point of the participants. With this access hopefully, readers can gain some understanding of the obstacles and triumphs that participants shared and use this insight to pursue new research questions. Only by continuing to conduct meaningful research can there be sufficient change to make the ASD diagnosis process better for all families.

Appendix A

Participant Interview Protocol
Hello, _____
Thank you for taking time to talk with me today. As you know this interview is related to your experience in obtaining an ASD diagnosis for [CHILD]. As I previously mentioned I will be recording this discussion if that is still fine with you. Thank you and I will begin the recording now. Can you start by telling me a little bit about yourself and your family?

1. Describe when you noticed that [CHILD] began behaving or developing differently. What symptoms led you to seek outside help? Did you talk with anyone else about what you noticed?
2. Tell me about the first appointment with the doctor to discuss [CHILD's] progression? What do you think could have made that first appointment better?
3. What was the road to the diagnosis like for you and your family? How long did it take from you noticing symptoms to getting the diagnosis for [CHILD]?
4. Describe the day when you were told that [CHILD] has ASD.
5. Tell me about your experience with the clinician that diagnosed [CHILD]? How was the communication throughout the process? Is there anything that you want clinicians to know?
6. Are there any ways that [CHILD's] diagnosis has impacted your family? How do you overcome when these issues happen?
7. What has been one of your best moments to date with [CHILD]? What are your hopes for [CHILD's] future?

Appendix B

AUTISM NEEDS ASSESSMENT

Please note that you must be at least 18 years of age to complete this survey

Thank you for agreeing to complete this survey. Since most respondents will be parents/guardians, we refer to the person with autism as "your child." The term autism is used to refer to all Autism Spectrum Disorders (ASD). Please complete this survey for your oldest child with autism. Mark only one answer choice per question unless otherwise specified.

1. Please identify yourself:

O Mother
O Father
O Foster parent
O Legal guardian

O Other *(Please specify)* _____

2. Which of the following best describes your current marital status?

O Married to/Living with child's other parent
O Married to/Living with person other than child's parent
O Widowed
O Never been married
O Separated/Divorced

3. What is your race/ethnicity? *(Check all that apply)*

O African American
O Asian/Pacific Islander
O Caucasian/European American
O Latino, Hispanic, or Chicano
O Native American

O Other *(Please specify)* _____

4. What is the race/ethnicity of your spouse or significant other? *(Check all that apply)*

O African American
O Asian/Pacific Islander
O Caucasian/European American
O Latino, Hispanic, or Chicano
O Native American
O N/A

O Other *(Please specify)* _____

5. What is your zip code (e.g. 19104)?

6. Which of the following is closest to your annual household income?

O Under $20,000
O $20,000-$39,999
O $40,000-$59,999
O $60,000-$79,999
O $80,000-$99,999
O $100,000 or above

7. What is your highest level of completed education?

O No high school
O Some high school
O High school graduate/GED
O Vocational/Technical school degree
O Some college
O College degree
O Some graduate studies
O Graduate

8. What is the sex of your child?

O Male
O Female

9. How old is your child? _____years _____months

10. Is your child adopted?

O Yes
O No

11. What is his/her race/ethnicity? *(Check all that apply)*

O African American
O Latino/Hispanic/Chicano
O Asian/Pacific Islander
O Native American
O Caucasian/European American

O Other *(Please specify)* _____

12. How many siblings does he/she have? _____

13. How many of those siblings have also been diagnosed with autism? ____

14. What is your child's primary diagnosis?

O Asperger's Disorder
O Autistic Disorder/Autism
O Childhood Disintegrative Disorder
O Pervasive Developmental Disorder (PDD/NOS)
O Rett Syndrome

O Other *(Please specify)* _____

15. Does your child **currently** have any of the following diagnoses? *(Check all that apply)*

O Anxiety Disorder
O Hearing Impairment

O Attention Deficit/Hyperactivity Disorder
O Bipolar Disorder
O Central Auditory Processing Disorder
O Conduct Disorder (CD)
O Depression
O Developmental Delays
O Learning Disability
O Mental Retardation/ Intellectual Disability
O Obsessive Compulsive Disorder (OCD)
O Oppositional Defiant Disorder (ODD)
O Seizures/ Seizure Disorder/Epilepsy
O None

O Other *(Please specify)* _____

16. Did your child receive any of the following diagnoses **prior** to receiving his/her autism diagnosis? (*Check all that apply*)

O Anxiety Disorder
O Attention Deficit/Hyperactivity Disorder
O Bipolar Disorder
O Central Auditory Processing Disorder
O Conduct Disorder (CD)
O Depression
O Developmental Delays
O Hearing Impairment
O Learning Disability
O Mental Retardation/ Intellectual Disability
O Obsessive Compulsive Disorder (OCD)
O Oppositional Defiant Disorder (ODD)
O Seizures/ Seizure Disorder/Epilepsy
O None

O Other *(Please specify)*

17. How old was your child when you first became concerned about his/her development?

_____years _____months

18. What type of professional first diagnosed your child with autism?

O Developmental Pediatrician
O Educational team (IEP or EI)
O Neurologist
O Primary Care Physician (Family doctor/Pediatrician)
O Psychiatrist
O Psychologist

O Other *(Please specify)* _____

19. About how many miles did you travel for the initial autism diagnosis (roundtrip)?

O 0-20 miles
O 21-40 miles
O 41-60 miles
O 61-80 miles
O 81-100 miles
O More than 100 miles

20. How old was your child when he/she received this diagnosis? _____years _____months

21. How many professionals (e.g. psychologist, developmental pediatrician) did you visit before your child received an autism diagnosis? _____

22. After receiving a diagnosis, what sort of follow-up and resources/services did you receive? (*Check all that apply*)

O Follow-up appointment
O Referral to a specialist for further assessment
O Referral to a specialist for treatment
O Referral to Early Intervention services
O Referral to support groups
O Referral to websites, literature (e.g. handouts, information booklets)
O None

O Other *(Please specify)* _____

23. How do you pay for your child's health care services? (*Check all that apply*)

O Private health insurance
O Medicaid (Medical Access)
O Out-of-pocket
O I don't know

O Other *(Please specify)* _

---

24. In the past year, have you taken your child to the emergency room for behavioral or psychiatric reasons?

O Yes
On how many occasions? ____
O No

25. In the past year, has your child been admitted to a hospital or hospital-like setting for behavioral or psychiatric reasons?

O Yes
On how many occasions? ____
O No

If you answered "No" to question 25, please SKIP to question 26

25a. What was/were the reason(s) your child was admitted to a hospital or hospital-like setting? *(Check all that apply)*

O Aggression
O Anxiety
O Defiant/Oppositional behaviors
O Depression
O Running away from home/school
O Self-injurious behaviors
O Significant increase in obsessions

O Other *(Please specify)* _____

25b-d. How satisfied or dissatisfied were you with the following aspects of your child's hospital stay?

	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied
b. Discharge Planning	**O**	**O**	**O**	**O**
c. Staff's Inclusion of Parent(s) in Treatment Planning	**O**	**O**	**O**	**O**
d. Quality of Treatment	**O**	**O**	**O**	**O**

25e. How was your child admitted?

O My child (under 14) was admitted by his/her parent(s)
O My adolescent child (14 to 18) was admitted by his/her parent(s) and agreed to the admission
O My adolescent child (14 to 18) was admitted by his/her parent(s) but did not agree to the admission
O My adult child (18 or older) admitted him/herself (201, voluntary treatment)
O My adult child (18 or older) was admitted against his/her will (302, involuntary treatment)

Please continue answering the questions

26. In the past year, has your child been placed in a residential facility?

O Yes

O No, but currently on a waiting list

O No and not on a waiting list

If your child has not been placed in a residential facility or is not currently on a waiting list, please SKIP to question 27

26a. About how many miles is this residential facility away from your home?

O 0-20 miles

O 21-40 miles

O 41-60 miles

O 61-80 miles

O 81-100 miles

O More than 100 miles

Please continue answering the questions

27. What is your child's current living situation?

O With parent(s) in a family home

O With other relative(s) in a family home with support

O Residential facility

O Group home

O Lives on own

O Lives on own without support

28. How satisfied or dissatisfied are you with your child's current living arrangement?

O Very Satisfied **O** Satisfied **O** Dissatisfied **O** Very Dissatisfied

29. Is your child receiving therapy or intervention for any of the following issues?

	Yes, and needs it	Yes, but does not	No, but needs	No, and does not need it
a. **Self-injurious behaviors**	**O**	**O**	**O**	**O**
b. **Sleep Problems**	**O**	**O**	**O**	**O**
c. **Anxiety**	**O**	**O**	**O**	**O**
d. **Aggressive Behaviors**	**O**	**O**	**O**	**O**
e. **Running Away**	**O**	**O**	**O**	**O**
f. **Toileting**	**O**	**O**	**O**	**O**

30. In the last year, has your child been disciplined at school in any of the following ways? *(Check all that apply)*

O Time-out/De-escalation room
O Sent out of classroom
O Detention
O In-school suspension
O Out-of-school suspension
O Expulsion
O None
O N/A (My child is not in school)

O Other *(Please specify)* _____

31. Has your child's behavior resulted in any of the following interactions with the police? *(Check all that apply)*

O Police called
O Served time in jail
O Police warning issued
O Served time in a juvenile detention facility
O Child adjudicated
O None

O Other *(Please specify)* _____

32. What long-term plans do you have for your child when you are no longer able to care for them? *(Check all that apply)*

O Arranged housing plans
O Designated power of attorney
O Set up financial trust
O Currently developing plans
O Designated guardianship
O None at this time

O Other *(Please specify)* _____

33. In what ways (if any) has your child's autism affected your family's workforce participation? *(Check all that apply)*

	Me	**My Partner**
a. **Stopped working outside the home**	**O**	**O**
b. **Decreased work hours**	**O**	**O**
c. **Increased work hours**	**O**	**O**
d. **Changed employer**	**O**	**O**
e. **Changed type of work**	**O**	**O**
f. **Changed work schedule**	**O**	**O**
g. **Changed position with same employer**	**O**	**O**
h. **Used Family Medical Leave Act**	**O**	**O**
i. **Lost promotion/advancement opportunities**	**O**	**O**
j. **Terminated from employment**	**O**	**O**
k. **Disciplined/Suspended**	**O**	**O**
l. **None**	**O**	**O**
m. **Other** *(Please specify)*	**O**	**O**

34. Does your child have an IEP *(Individualized Education Plan)?*

O Yes
O No, but evaluation complete, waiting for results
O No, but waiting for an evaluation
O No
O I don't know

If your child DOES NOT have an IEP, please SKIP to question 35

34a. How strongly do you agree or disagree with the following statement?
"My child's IEP addresses all of my concerns for my child's development and education."

O Strongly Agree **O** Agree **O** Disagree **O** Strongly Disagree

34b. Did you or another family member attend your child's last IEP meeting?

O Yes **O** No

Please continue answering the questions...

35. In what category of special education is your child currently placed? *(Check all that apply)*

O Autism
O Mental Retardation
O Emotional Support Disabilities
O Multiple Disabilities
O Learning Disabilities
O None (My child is not receiving special education services)

O Other *(Please specify)*_____

36. Is your child capable of the following activities?

	Independentl	With Help	Not Capable
a. **Toileting**	**O**	**O**	**O**
b. **Feeding self**	**O**	**O**	**O**
c. **Dressing self**	**O**	**O**	**O**
d. **Requesting things he/she needs**	**O**	**O**	**O**
e. **Requesting things he/she wants**	**O**	**O**	**O**
f. **Indicating when he/she is sick/hurt**	**O**	**O**	**O**

37. Does your child have any siblings?

O Yes
O No

Please answer questions 37 a-q in regard to the sibling closest in age to your child with autism, even if this sibling does not have autism.

If your child does not have any siblings, please SKIP to question 38.

37a. How old is this sibling? years _____ months

37b. What is his/her sex?

- **O** Male
- **O** Female

37c. Does this sibling currently live in the same home as your child with autism?

- **O** Yes
- **O** No

37d. What is his/her relationship to your child with autism?

- **O** Biological siblings
- **O** Adoptive siblings
- **O** Half-siblings
- **O** Stepsiblings
- **O** Other *(please specify)*

37e. Does this sibling have any of the following diagnoses? *(Check all that apply)*

O Anxiety Disorder
O Attention Deficit/Hyperactivity Disorder
O Autistic Disorder/Autism
O Bipolar Disorder
O Central Auditory Processing Disorder
O Conduct Disorder (CD)
O Depression
O Developmental Delays
O Hearing Impairment
O Learning Disability
O Mental Retardation/ Intellectual Disability
O Obsessive Compulsive Disorder (OCD)
O Oppositional Defiant Disorder (ODD)
O Seizures/ Seizure Disorder/Epilepsy
O None
O Other *(Please specify)* _____

37f-q. Based on this sibling's behavior in the past six months, how often has he/she demonstrated the following behaviors compared to his/her peers . ***"This child …"***

	Never	Sometimes	Often	Almost Always
f. **Was physically aggressive**	**O**	**O**	**O**	**O**
g. **Was verbally aggressive**	**O**	**O**	**O**	**O**
h. **Seemed anxious**	**O**	**O**	**O**	**O**
i. **Seemed depressed**	**O**	**O**	**O**	**O**
j. **Made suicidal threats/comments**	**O**	**O**	**O**	**O**
k. **Exhibited suicidal/self-harming behaviors**	**O**	**O**	**O**	**O**
l. **Complained that no one loves/cares about him/her**	**O**	**O**	**O**	**O**
m. **Complained about his/her sibling with autism**	**O**	**O**	**O**	**O**
n. **Had conflicts with parents**	**O**	**O**	**O**	**O**

o. **Had conflicts with his/her sibling with autism**	**O**	**O**	**O**	**O**
p. **Had conflicts with peers**	**O**	**O**	**O**	**O**
q. **Had conflicts with authority figures**	**O**	**O**	**O**	**O**

Please continue answering the questions about your oldest child with autism

38. How strongly do you agree or disagree with the following statements?

"My child is receiving all the regular care he/she needs for…"

	Strongly	Agree	Disag	Strongly
a. **Primary Health**	**O**	**O**	**O**	**O**
b. **Dental Services**	**O**	**O**	**O**	**O**

"The individuals providing these services are able to meet my child's needs."

	Strongly	Agree	Disag	Strongly
c. **Primary Health**	**O**	**O**	**O**	**O**
d. **Dental Services**	**O**	**O**	**O**	**O**

39. What limitations do you face accessing primary health care? *(Check all that apply)*

O Transportation
O Scheduling issues
O Child's behavior problems
O Shortage of service providers in the area
O No service providers in the area
O Providers in the area won't see children with autism
O Cost of services/My insurance does not cover available services
O None

O Other *(Please specify)* _____

O Other *(Please specify)* _____

40. What limitations do you face accessing dental services? *(Check all that apply)*

O Transportation
O Scheduling issues
O Child's behavior problems
O Shortage of service providers in the area
O No service providers in the area
O Providers in the area won't see children with autism
O Cost of services/My insurance does not cover available services
O None

O Other *(Please specify)* _____

O Other *(Please specify)* _____

41. Please tell us about your child's specialty health and education service needs:

	My child is receiving	My child is receiving, but	My child is receiving, but	My child is not receiving	My child is not receiv
a. **Mental Health Co**	**O**	**O**	**O**	**O**	**O**

b. **Speech/Language Th**	**O**	**O**	**O**	**O**	**O**
c. **Occupational Therapy**	**O**	**O**	**O**	**O**	**O**
d. **Physical Therapy**	**O**	**O**	**O**	**O**	**O**
e. **Social Skills Training**	**O**	**O**	**O**	**O**	**O**
f. **One-to-one Support (not TSS)**	**O**	**O**	**O**	**O**	**O**
g. **Mobile Therapy**	**O**	**O**	**O**	**O**	**O**
h. **Case Management**	**O**	**O**	**O**	**O**	**O**
i. **Neurology Services**	**O**	**O**	**O**	**O**	**O**
j. **Medication Management**	**O**	**O**	**O**	**O**	**O**
k. **Summer Camp**	**O**	**O**	**O**	**O**	**O**
l. **Summer School (ESY)**	**O**	**O**	**O**	**O**	**O**
m. **Sexual Health Education**	**O**	**O**	**O**	**O**	**O**

42. How strongly do you agree or disagree with the following statement?
"The professionals providing this service have the necessary skills to work with my child."

	Strongly Agree	Agree	Disagree	Strongly Disagree	N / A
a. **Mental Health Counseling**	**O**	**O**	**O**	**O**	**O**
b. **Speech/Language Therapy**	**O**	**O**	**O**	**O**	**O**
c. **Occupational Therapy**	**O**	**O**	**O**	**O**	**O**
d. **Physical Therapy**	**O**	**O**	**O**	**O**	**O**
e. **Social Skills Training**	**O**	**O**	**O**	**O**	**O**
f. **One-to-one Support (e.g. TSS)**	**O**	**O**	**O**	**O**	**O**
g. **Mobile Therapy**	**O**	**O**	**O**	**O**	**O**
h. **Case Management**	**O**	**O**	**O**	**O**	**O**
i. **Neurology Services**	**O**	**O**	**O**	**O**	**O**
j. **Medication Management**	**O**	**O**	**O**	**O**	**O**
k. **Summer Camp**	**O**	**O**	**O**	**O**	**O**
l. **Summer School (ESY)**	**O**	**O**	**O**	**O**	**O**
m. **Sexual Health Education**	**O**	**O**	**O**	**O**	**O**

43. How strongly do you agree or disagree with the following statement?
"This service is effective in meeting my child's needs."

	Strongly Agree	Agree	Disagree	Strongly Disagree	N / A
a. **Mental Health Counseling**	**O**	**O**	**O**	**O**	**O**
b. **Speech/Language Therapy**	**O**	**O**	**O**	**O**	**O**
c. **Occupational Therapy**	**O**	**O**	**O**	**O**	**O**
d. **Physical Therapy**	**O**	**O**	**O**	**O**	**O**
e. **Social Skills Training**	**O**	**O**	**O**	**O**	**O**
f. **One-to-one Support (e.g. TSS)**	**O**	**O**	**O**	**O**	**O**
g. **Mobile Therapy**	**O**	**O**	**O**	**O**	**O**
h. **Case Management**	**O**	**O**	**O**	**O**	**O**
i. **Neurology Services**	**O**	**O**	**O**	**O**	**O**
j. **Medication Management**	**O**	**O**	**O**	**O**	**O**
k. **Summer Camp**	**O**	**O**	**O**	**O**	**O**
l. **Summer School (ESY)**	**O**	**O**	**O**	**O**	**O**
m. **Sexual Health Education**	**O**	**O**	**O**	**O**	**O**

44. What limitations do you face accessing the specialty health and education services mentioned? *(Check all that apply)*

O Transportation

O Providers in the area won't see

O Scheduling issues children with autism

O Child's behavior problems

O Cost of services/My insurance does not cover

O Shortage of service providers in the area

available services

O No service providers in the area

O None

O Other *(Please specify)* _____

O Other *(Please specify)* _____

45. Please tell us about your family support service needs:

	My family is receiving	My family is receiving, but needs	My family is receiving, but does	My family is not receiving, but needs	My family is not receiving
a. **Respite Care**	**O**	**O**	**O**	**O**	**O**
b. **Babysitting**	**O**	**O**	**O**	**O**	**O**
c. **Afterschool Care**	**O**	**O**	**O**	**O**	**O**
d. **Weekend Childcare**	**O**	**O**	**O**	**O**	**O**
e. **Family Counseling**	**O**	**O**	**O**	**O**	**O**
f. **Sibling Support Groups**	**O**	**O**	**O**	**O**	**O**
g. **Sibling Mental Health Counseling**	**O**	**O**	**O**	**O**	**O**
h. **Parent Support Groups**	**O**	**O**	**O**	**O**	**O**
i. **Parent Mental Health Counseling**	**O**	**O**	**O**	**O**	**O**

46. How strongly do you agree or disagree with the following statement?
"The professionals providing this service have the necessary skills to work with my family."

	Strongly Agree	Agree	Disagree	Strongly Disagree	N / A
a. **Respite Care**	**O**	**O**	**O**	**O**	**O**
b. **Babysitting**	**O**	**O**	**O**	**O**	**O**
c. **Afterschool Care**	**O**	**O**	**O**	**O**	**O**
d. **Weekend Childcare**	**O**	**O**	**O**	**O**	**O**
e. **Family Counseling**	**O**	**O**	**O**	**O**	**O**
f. **Sibling Support Groups**	**O**	**O**	**O**	**O**	**O**
g. **Sibling Mental Health Counseling**	**O**	**O**	**O**	**O**	**O**
h. **Parent Support Groups**	**O**	**O**	**O**	**O**	**O**
i. **Parent Mental Health Counseling**	**O**	**O**	**O**	**O**	**O**

47. How strongly do you agree or disagree with the following statement?
"This service is effective in meeting my family's needs."

	Strongly Agree	Agree	Disagree	Strongly Disagree	N / A
a. **Respite Care**	**O**	**O**	**O**	**O**	**O**
b. **Babysitting**	**O**	**O**	**O**	**O**	**O**
c. **Afterschool Care**	**O**	**O**	**O**	**O**	**O**
d. **Weekend Childcare**	**O**	**O**	**O**	**O**	**O**
e. **Family Counseling**	**O**	**O**	**O**	**O**	**O**
f. **Sibling Support Groups**	**O**	**O**	**O**	**O**	**O**
g. **Sibling Mental Health Counseling**	**O**	**O**	**O**	**O**	**O**
h. **Parent Support Groups**	**O**	**O**	**O**	**O**	**O**
i. **Parent Mental Health Counseling**	**O**	**O**	**O**	**O**	**O**

48. What limitations do you face accessing the family support services mentioned? *(Check all that apply)*

O Transportation services/My insurance does not
O Scheduling issues services
O Shortage of service providers in the area
O No service providers in the area
O Cost of cover available
O None

O Other *(Please specify)* _____

O Other *(Please specify)* _____

49. Are there any particular service providers or organizations you would recommend to other individuals?

(Please fill out as much information as possible)

Type of Service:	
Name of Provider:	
Organization:	
Address:	

Type of Service:	
Name of Provider:	
Organization:	
Address:	

Type of Service:	
Name of Provider:	
Organization:	
Address:	

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